'Appraising Self-advocacy in the Lives of People with Learning Difficulties'

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Summary

This thesis presents an appraisal of self-advocacy in the lives of people with learning difficulties ('self-advocates'). The study consists of thesis (volume I) and appendix (volume II). The thesis attempts to answer three questions:

1. What is the nature of the contemporary self-advocacy movement?
2. How do self-advocacy groups impact upon the lives of people with learning difficulties?
3. How do self-advocacy groups work?

The first section of the thesis reviews the literature on self-advocacy of people with learning difficulties, introduces an inclusive social model of disability (the guiding theoretical perspective of this appraisal) and critically outlines the methods employed in this study. The next three sections present findings from the empirical work:

- Section 2 – *The nature of the contemporary self-advocacy movement* – reports on the findings from a postal survey of 134 self-advocacy groups, highlighting the complexity within the movement, overlap of group types and variety of group affiliations.
- Section 3 – *Living self-advocacy* – presents the life stories of five self-advocates who have had long-term involvement with self-advocacy groups. Broad themes are drawn out from the stories, including life before self-advocacy groups, coming out as a self-advocate and expert advice. Attention is also paid to the writing of life stories in collaborative narrative inquiry.
- Section 4 – *Self-advocacy in action* – delves into the dynamics of four self-advocacy groups as gleaned through an ethnographic study. Each group is described and appraised, the self-advocacy literature is revisited in light of the observed workings of groups and the notion of support is considered with reference to models of disability. Finally, the doing of ethnography is explored with reference to subjectivity, method and analysis.

The final section of the thesis revisits self-advocacy in light of the empirical findings. It is concluded that even when self-advocates are disabled by excluding barriers and stifled by the 'support' of others and the affiliations of their self-advocacy groups, their resilience shines through.

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Acknowledgements

Declaration

I declare that this thesis has been composed by myself and that the research reported here has been conducted by myself unless otherwise indicated.

Chapter 1

Introduction - Appraising self-advocacy in the lives of people with learning difficulties

Introduction

This thesis appraises self-advocacy in the lives of people with learning difficulties. The term learning difficulties is used to describe people who have been labelled at some point in their lives as requiring specialist 'mental handicap services' (Walmsley 1993, p46). 'Learning difficulties' is chosen instead of other synonyms such as 'mental handicap', 'mental impairment' or 'learning disabilities', because it is the term preferred by many in the self-advocacy movement[1]:

'If you put 'people with learning difficulties' then they know that people want to learn and to be taught how to do things' (A self-advocate quoted in Sutcliffe & Simons 1993, p23).

Hitherto, a number of studies have examined self-advocacy in self-advocacy groups and in other areas of people with learning difficulties'

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[1] See *Huddersfield People First* undated, *People First Liverpool* 1996 and publications by *People First London* including *'Making it easy first'* project, *Outside But Not Inside...Yet, Your Right to Housing and Support, Safer Sex Pack, Oi! It's My Assessment, Laws About Our Rights - Civil Rights (Disabled Persons) Bill.*

lives[2]. This study adds to this literature by considering the ways in which people with learning difficulties ('self-advocates') speak up for themselves, individually and collectively, in spite of a disabling society. A number of sources are drawn upon to examine the self-advocacy movement, some groups within it and individual self-advocates' life experiences. Also, links are made with literature of the social model of disability[3] and literature concerned with the sociological bases of learning difficulties[4] - thus making for an inclusive social model of disability. This study aims to answer three research questions:

1. What is the nature of the contemporary self-advocacy movement?

2. How do self-advocacy groups impact upon the lives of people with learning difficulties?

3. How do self-advocacy groups work?

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[2] See for example Shearer 1972, 1973, Hanna 1978, Crawley 1982, 1988, 1990, Williams 1982, Williams and Shoultz 1982, Worrel 1987, 1988, Simons 1992, Sutcliffe and Simons 1993, Hampson 1994, Dybwad and Bersani 1996, Mitchell 1997, Shoultz 1997a, 1997b, 1997c.

[3] See for example Finkelstein 1981, Abberley 1987, Oliver 1990, 1996, Morris 1991, 1996, Barnes 1990, 1991, BCODP 1992, Campbell and Oliver 1996, Shakespeare 1993b, Shakespeare and Watson 1997.

[4]See for example, Dexter 1956, 1958, Edgerton 1967, Hunt 1967, Dingham 1968, Braginsky and Braginsky 1971, Deacon 1974, O'Donnell 1976, Bogdan and Taylor 1976, 1982, Turner 1980, Brechin, Liddiard and Swain 1981, Kurtz 1981, Brechin and Walmsley 1989, Whittemore, Langness and Koegel 1986, Lea 1988, Fido and Potts 1989, Atkinson and Williams 1990, Potts and Fido, 1991, Oswin 1991, Cheston 1994, Booth and Booth 1994.

The work from this study is encompassed in two volumes – thesis (Volume I) and appendices (Volume II)

Volume I – Thesis

The thesis is split into five sections. Section 1, reviews the self-advocacy literature, introduces an inclusive social model of disability and critically introduces the methods that are used in this appraisal. Section 2, the first empirical section of the thesis, attempts to answer research question 1. The state of the self-advocacy movement in the 1990s is described and examined with reference to findings from a postal survey of 134 self-advocacy groups. The next two empirical sections explore self-advocacy qualitatively:

> 'Qualitative research is so valuable to disability studies: It gives a voice to people who are often studied but seldom heard. The use of techniques such as participant observation, in-depth interviews, life stories and document analysis permits the researcher to blur the edges that often separate people with disabilities from the rest of society' (Ferguson, Ferguson & Taylor 1992b, p14)

Section 3 draws upon the life stories of five top self-advocates – people with learning difficulties who have had extensive experience of self-advocacy groups. These stories are used to examine the impact of self-advocacy groups upon the life experiences of a few self-advocates (research question 2). Life stories are presented and analysed and the writing process is explored.

Section 4, the third and final empirical section, is based upon an ethnographic study of four self-advocacy groups that took place over a period of 14 months. This section addresses how self-advocacy groups work, how they are organised, what processes occur, what support is offered and what self-advocates get out of group membership (research question 3). Finally, section 5 revisits many of the controversies and questions raised in the first section, in light of the empirical findings, in appraising self-advocacy in the lives of people with learning difficulties.

Summary of chapters

Section 1 – Setting the scene

This introductory section begins with chapter 2, which reviews the literature on self-advocacy of people with learning difficulties. First, individual and collective self-advocacy will be defined. Second, because the literature usually considers collective self-advocacy as occurring in self-advocacy groups, and these groups have been identified as forming a 'new social movement', the origins of the movement are traced. Third, the components of groups are presented and some of the controversies inherent in the different ways in which self-advocacy groups are organised are examined. Finally, it is concluded that self-advocacy constitutes a personal and political activity with potentially massive impacts upon the lives of people with learning difficulties and, therefore, deserves appraisal. Three questions are posed that form the focus of this thesis.

Chapter 3 sets out an inclusive social model of disability, the theoretical perspective that guides this thesis. Attention is drawn to the socio-historical, cultural and political bases of disability. It is argued that an awareness of the social bases of disability is a pre-requisite for an appraisal of self-advocacy. First, the individual and social models of disability are presented. Then, links will be made between the social model and literature that considers learning difficulties as a social construction. Finally, it is concluded that the appraisal of self-advocacy offered in this thesis, which is grounded in the experiences, stories and actions of people with learning difficulties, will draw upon, and in some small build upon, an inclusive social model of disability. This chapter draws upon a previous paper (Goodley 1996c).

Following on from the theoretical and literature reviews, chapter 4 sets out and critically evaluates those methodologies, methods and analyses that are employed to answer the three questions. A postal survey of self-advocacy groups is employed to gain a glimpse into the current state of the self-advocacy movement. Life stories of five self-advocates are collected to see how self-advocacy group membership impacts upon life experiences. An ethnographic study of four self-advocacy groups is adopted to uncover some of the dynamics of self-advocacy groups in action.

Section 2 – The nature of the contemporary self-advocacy movement: Surveying self-advocacy

In 1992 Simons estimated that there were approximately 500 self-advocacy groups in the UK (Simons 1992). Chapter 5 presents the findings from a postal survey of 134 groups in Britain. The analysis is split into three sections. First, the responses to each item on the survey are summarised.

Second, the findings from a thematic analysis of group discussion topics are presented. Third, responses are analysed to see if and how groups fit into the typology of groups identified in the literature (chapter 2). While this postal survey provides a useful account of the movement's complexity, questions remain about the lived experiences and actions that go on under the banner of self-advocacy. Consequently, the thesis moves deeper into the self-advocacy movement through the use of qualitative methods.

Section 3 – Living self-advocacy: Stories of self-advocates

Chapter 6 presents the life stories of five top self-advocates. Four of the stories are collaborative efforts between their narrators and me. One narrator wrote her own story, which is presented in chapter 6, while our collaborative effort is presented in *Appendix 3, 5*.

The life stories were collected to examine the impact of self-advocacy groups upon the lives of people with learning difficulties. In addition, narrators introduced a number of themes that went beyond this original research question. These broader themes are explored in chapter 7. Analysis falls into four sections. The first, 'Pre self-advocacy group days – the making of a self-advocate', traces narrators lives from childhood to adulthood prior to joining self-advocacy groups. The second, 'Being in self-advocacy groups – coming out as a self-advocate', examines the impact of groups on the continuing development of narrators' self-advocacy. The third, 'Learning from experience – expert advice on self-advocacy', draws together narrators' opinions on the workings of groups and the movement. The fourth and final section, 'Looking at stories – the self-advocacy group

and resilience', considers a number of general lessons that may be learnt about life as a self-advocate. The life stories illuminate the struggles of narrators throughout their life courses and highlight how self-advocacy groups enhance self-determination.

Chapter 8 moves away from an analysis of stories to a consideration of writing stories. In this chapter a research story is told to account for the stages of collaborative narrative inquiry that created the life stories presented in chapter 6. In part one of the research story, a number of issues are considered in relation to interviewing people with learning difficulties. Part two introduces writing techniques that were used to illustrate how spoken words (interview material) were turned into written text (stories). Part three illustrates how narrators became writers and critically considers the relationship between narrative inquiry and 'empowering' disability research. The story ends with a tale of a research relationship that looks closer at the collaborative nature of life story research. This chapter builds upon previous papers (Goodley 1996b, 1996d, 1997b, 1997c, in press, b).

Section 4 - Self-advocacy in action: Ethnographic study with four groups

Chapter 9 constitutes the first of three chapters that turn away from stories of self-advocates to actions in self-advocacy groups. This chapter describes and appraises self-advocacy in action in four groups. After describing how groups are organised, ethnographic involvement is used to appraise a number of points that emerge from previous literature (chapter 2) about the organisation, workings and processes within groups. In all, 12 points are assessed including the role of the professional supporter, the influences of

service systems, the role of the 'social' self-advocacy group, the notion of group independence, the affect of advocacy sponsorship and the bureaucratisation of self-advocacy. From this analysis it would appear that previous literature has simplified the multi-faceted dynamics within groups and ignored the inter-dependence amongst self-advocates that emerges in the various 'types' of self-advocacy group.

In view of the inadequacy of previous literature, Chapter 10 takes further the challenge of appraising self-advocacy in action by focusing on 'support'. First, the support offered by advisors is addressed. Drawing upon field notes it is suggested that previous literature has failed to account for the multi-faceted nature of support. This failure has resulted in simplistic attacks on professional (staff) advisors, a lack of conceptualisations of support that are grounded in models of disability, and has ignored the self-determination of self-advocates with learning difficulties themselves. Presented in this chapter are vignettes of support ('interventions') offered by advisors that can be seen as either empowering or disempowering. Interventions are understood in terms of where they lie on a continuum of support, where at one end is the Social Model of Disability and the other end the Individual Model of Disability. Five pairs of intervention are presented reflecting polar ends of the social-individual model continuum. With reference to disability theory presented in chapter 3, it is argued that those interventions that are drawn towards the social model end of the continuum offer a more authentic means of promoting self-advocacy skills inside groups. Second, in addition to the support of advisors, the inter-support networks of self-advocates are presented. By looking across groups it is concluded that collective self-advocacy reflects dynamics that are made

up of various interactions, which in turn, can be understood as reflecting different discourses of disability. This chapter builds upon previous papers (Goodley 1997a, 1997b, 1998, in press, a).

Similar to section 3, the final chapter in section 4 considers a number of methodological issues. Chapter 11 examines some issues associated with method and analysis in the doing of ethnographic research. Running in parallel to the research for this thesis was my involvement as a volunteer to a self-advocacy group. This section will explore how these two experiences were connected. I will consider how learning to be a volunteer helped me build up what I will call a 'researcher template'. This template provided me with a working framework through which to control, temper, assess and check some of my observations and analyses. First, researcher subjectivity with respect to 'knowing' research participants will be considered. Second, the ways in which my involvement as a volunteer impacted upon the doing of ethnography will be examined. Third, a number of dilemmas that I faced in participating in people's lives will be explored. In conclusion, a number of questions are posed and links are made between my ethnography and participatory research.

Section 5 - Revisiting self-advocacy & the social model

Chapter 11 draws the thesis to a close by revisiting self-advocacy in light of the empirical findings. The first part reflects upon what the study set out to uncover by recapping on the initial literature review, reiterating the theoretical bases of the thesis and critically summarising how the study set out to appraise self-advocacy.

The second part draws together a number of analytical connections from the empirical sections of the thesis. These include variation and complexity in the movement, the impacts of group 'type' and organisational dynamics, supporting self-advocacy, a priori resilience of people with learning difficulties, groups as a context for furthering self-advocacy, self-advocacy and self-definition, inter-dependence and culture and the need for self-advocates to call the shots.

The third and final part presents a number of questions that remain unanswered and therefore point ways forward for future research. A number are outlined, including self-advocacy and impairment, commonality between self-advocates and other disabled activists, the self-advocacy movement and the disability movement, leaving self-advocacy, types of self-advocacy and participatory research - a framework for future research.

Volume II - Appendices

This second volume contains the appendices to the thesis. Section 1 details publications and conference papers that came out of this study. Two of these papers are presented in full (Goodley 1996a, 1997a). Section 2 includes postal survey documents including the survey pack and SPSS coding details. Section 3, life story appendices, includes the handout that was given to narrators introducing the research, extracts from annotated narratives, correspondence details, 'my story' that I wrote for one of the narrators, details of access and meetings with narrators. Finally, section 4, ethnography appendices, presents introductory handouts that were given to

groups to negotiate access and to initiate group discussions, correspondence details, feedback reports from group discussions and a number of accessible reports and leaflets that were produced for groups.

Conclusion

This chapter has introduced the study, the structure of the thesis and contents of the appendix. The next chapter starts my appraisal of self-advocacy in the lives of people with learning difficulties. This thesis aims to build upon and contribute to previous understandings of self-advocacy.

Section 1

Setting the Scene

Chapter 2

Self-advocacy and people with learning difficulties

Introduction

'Once upon a time I wouldn't speak out at all. I used to be told to shut up. Now that I've been around a self-advocacy group I have learned to say what I want to say' (The views of a member, *People First Liverpool*, 1996, p2).

This chapter reviews the literature on self-advocacy of people with learning difficulties. First, individual and collective self-advocacy will be defined. Second, because the literature usually considers collective self-advocacy as occurring formally in self-advocacy groups, and these groups have been identified as forming a 'new social movement', the origins of the movement are traced. Third, the components of groups are presented and some of the controversies inherent in the different ways in which self-advocacy groups are organised are examined. Finally, it is concluded that self-advocacy constitutes a political activity with potentially massive impacts upon the lives of people with learning difficulties and, therefore, deserves appraisal. Three questions are posed that form the focus of this thesis.

What is self-advocacy?

'Self-advocacy enables us to make choices and make our decisions and control the way that our lives should be made' (Gary Bourlet 1988, a person with learning difficulties and a former president of *People First London*).

Sutcliffe and Simons (1993) observe that 'self-advocacy' is difficult to define. It means so much to so many and has grown in complexity over the years. To self-advocate is to advocate for yourself. It is different from advocacy, where someone else speaks up and represents you (Crawley 1988, Flynn and Ward 1991). Instead, as Williams and Shoultz (1982, p159) put it, self-advocacy is speaking or acting for yourself. It means deciding what's best for you and taking charge of getting it - standing up for your rights as a person. In a recent paper, Mitchell (1997b) suggests that 'self-advocating' is congruent with 'acting like an adult'. This is perhaps problematic. After all, how many adults without learning difficulties talk about 'self-advocating'? Therefore, following Bhavnani (1991), the term self-advocacy has been applied to account for the self-determination of minority groups who have historically been denied a 'voice'. The self-advocacy of people with learning difficulties has been increasingly recognised over the last three decades (Miller and Keys 1996). Self-advocacy passes as other terms such as 'speaking out', 'talking up', 'shouting up for your rights' and 'self-help' (Crawley 1982, Williams and Shoultz 1982, Cooper and Hersov 1986, Worrel 1988, Amans and Derbyshire 1989, Simons 1992, Sutcliffe and Simons 1993, *People First Liverpool* 1996, *Huddersfield People First* undated, Miller and Keys 1996, Kennedy 1997, O'Brien and Lyle O'Brien 1997). In all definitions, the self-

determination of people with learning difficulties is emphasised and members of this labelled group are referred to as *self-advocates*.

Self-advocacy can 'be done' by a person individually or in a group (Williams 1982, p3, Williams and Shoultz 1982, Mittler 1984, McKenna 1986, Crawley 1990, Brooks 1991, Sutcliffe and Simons 1993, Brickerhoff 1993, Hampson 1994, Greasley 1995, Shoultz 1997a, 1997b, 1997c). In the former case, Simons (1992, p5) refers to self-advocacy as:

> 'A process of individual development through which a person comes to have the confidence and ability to express his or her *own* feelings and wishes'.

According to Clare (1990), Sutcliffe (1990), Sutcliffe and Simons (1993) amongst others, self-advocacy on an ***individual level*** can refer to expressing thoughts and feelings in an assertive way, being able to make choices and decisions, having a clear knowledge about your rights and being able to make changes to your lifestyle. This may appear in formal contexts, such as Individual Programme Plans (IPPs, see Sutcliffe and Simons 1993 and Greasley 1995), career interviews or educational set-ups (Sievert, Cuvo and Davis 1988, Clare 1990, Phillips 1990) and Centres, homes and hospitals (Crawley 1982, 1988, Brooks 1991). In addition, self-advocacy appears to be associated with informal relationships with others: whether it is with friends (Taylor and Bogdan 1989, Goode 1992) or family (Simons 1992, Mitchell 1997b) in childhood (Brickerhoff 1993) or adulthood (Daniels 1982).

Much of the literature appears to suggest a mutually inclusive relationship between individual and *collective* self-advocacy. The link between sticking up for yourself on your own *and* with (and for) others is highlighted in the comments of a number of informants with learning difficulties in Simons' study (1992, quotes taken from pp18-20). Simons found from his informants that self-advocacy meant self-expression ('It's sticking up for yourself'), highlighted the ability to represent self and others ('helping people worse off than yourself') and gave a context for self-development ('it gives you confidence - and then people have confidence in you'). Informants collectively voiced and acted upon complaints ('We talked about the lack of seat-belts in the minibus'), explored issues of integration ('The main issue is community living') and gave a place to appraise service provision ('Talking about things that could be done in Centres... how we could all make things better. It's a ceaseless battle to get more houses'). According to Hanna (1978) and Worrel (1987, 1988), amongst others, this collective aspect of self-advocacy is most clearly observable in *self-advocacy groups*. Previous literature has tended to focus on the doing of self-advocacy in the formal context of groups.

As with the generic term of self-advocacy, groups go under many names, such as 'speaking out', 'trainee committees' and 'working groups' (Crawley 1982, 1988). One of the most common labels in the literature is that of *People First* (see for example Hanna 1978, Worrel 1987, 1988, Crawley 1990, Dybwad and Bersani 1996). *People First Liverpool* (1996) provide a useful introduction to their group:

'We are a group of People with Learning Difficulties, who are learning to speak out and trying to help other people to speak out for

themselves. We have meetings every fortnight, where we talk about whatever people want to talk about. We elect a chair, a secretary, a treasurer and a vice-treasurer. We employ two people to support us. We run training courses about self-advocacy ... we also do evaluations of services and talks in colleges. We run training courses for staff on how staff should treat us, they should treat us with respect. We go to meetings with bosses and speak out about how the service users feel, and how they should be treated'.

Self-advocacy within groups, as will be shown later, can serve many functions and is organised in different ways (Simons 1992, Kennedy 1997). For now it would prove useful to trace the history of these groups, who make up what is known as the self-advocacy movement.

The history of the self-advocacy movement

'Empowerment is a process. Power is not given to people nor is it earned. It happens as a result of a constructive, meaningful activity that leads people to be more knowledgeable, skilful, informed and aware than they were before' (Worrel 1988, p7).

The self-advocacy movement is a living testament to the resource of group activity by people with learning difficulties in challenging institutionalised prejudice and oppressive hegemony within society (Williams and Shoultz 1982, Bramley and Elkins 1988). It is impossible to ascertain when self-advocacy started. As Campbell and Oliver (1996) point out, in their historical account of the British disability movement over the last 30 years, disabled people were self-organising long before the 1960s. The same can

be said about people with learning difficulties. Instead, the few accounts of the history of self-advocacy appear to start from the time when 'self-advocacy' was formally recognised and defined by people without learning difficulties some 30 years ago[1].

Beginnings

According to Crawley (1982), Williams and Shoultz (1982), Browning, Thorin and Rhoades (1984), Bersani (1996), Dybwad (1996), Hersov (1996), Perske (1996) and Shoultz (1997b, 1997c), the origins of the movement can be traced back to the late 1960s. In Sweden, a small group of people with learning difficulties developed a list of requests about how their services should be provided (Shoultz 1997b). They gave this list to the parent organisation that supported them. Whether or not the requests were acted on remains unknown (Ibid.), but something unprecedented and previously undocumented had occurred. Perske (1996, pp20-21) describes another similar episode:

> 'STOCKHOLM, SWEDEN, November 8, 1969. Ten persons with mental retardation and six university students - all good friends - came together for a special adventure. [They meet in a club and go to the theatre]. The sixteen went to a coffee shop and discussed all that they had experienced. Everyone decided that they wanted to see the play at a later date. So, they began making a checklist of preparations. As they left, the group decided not to return to the club.

[1] As Potts and Fido (1991) put it, people with learning difficulties have consistently had their histories written for by others - from careworker and psychologist to historian and social scientist.

They agreed to break up at this new and strange location and each find his or her own way home'.

Perske (1996) suggests that Bengt Nirje, a principle writer of normalisation principles (along with Wolfensberger 1972b, in the USA), used the scenario presented above in formulating ideas about 'risk-taking' for people with learning difficulties. Early normalisation principles and the beginnings of self-advocacy were complementary (see O'Brien 1987, Lawson 1991, Brown and Smith 1992a and b). The 1st and 2nd Swedish National Conferences of Retarded Adults in 1968 and 1970 were staged when the views of people with learning difficulties were starting to be formally recognised (Crawley 1982, p70). Around the same time, two conferences in America contributed substantially to public visibility of adults with learning difficulties (Dybwad 1996). The first was the 35th Spring Conference at a school in Massachusetts, entitled 'Outlook for the Adult Retarded', which debated the social impact of the increasing life spans of people with learning difficulties. The other, the Golden Anniversary White House convention on Children and Youth, saw one of the first questions to be publicly raised over the legal status of the mentally retarded adult and child (Ibid.). These were amongst the earliest documented conferences in which the experiences of people with learning difficulties were of primary interest. In 1969 at the 3rd National Youth Conference on Mental Retardation in Miami, a panel of young adults with learning difficulties discussed their personal reactions to work programs. This kind of overt participation represented a radical new departure (Ibid., Shoultz 1997b).

These events in Sweden and America (and Canada, see Shoultz 1997c, and for Australia see Bramley and Elkins 1988) inspired what became known as 'participation events' in the UK (Crawley 1982, Hersov 1996, *People First Liverpool* 1996). The first one (*'Our Life'* in June 1972) organised by the Campaign for Mentally Handicapped People (CMH), brought together a number of residents from long-stay hospitals to talk about where they would like to live in the future. When written up (Shearer 1972) it was the first publication in the UK to be wholly made up of the comments by 'mentally handicapped' people about the services they received (Hersov 1996). The following year another conference took place (*'Listen'* see Shearer 1973). This considered relationships, choices and independence, with another workshop on participation occurring soon afterwards (see Fiona Williams' report in 1973). According to Crawley (1982), the next two in 1974 and 1975 had delegates discussing experiences of employment. Hersov (1996) states that these events had an immeasurable impact upon the UK self-advocacy movement. *'Listen'* (1973), for example, cites delegates articulating views on aspects of life including relationships (with each other, family and staff), and choice and independence. For Shearer (1973), the CMH meetings taught those professionals and researchers who were present, of the sharp perceptions held by delegates with learning difficulties, of their entirely realistic desire to share experiences and of the ways in which disabilities are imposed by society's preoccupation with impairment. On writing up the *'Listen'* conference report, Shearer's concerns and ambitions typify many feelings prominent in the early days:

> "'Listen' and 'Our Life' have shown the potential for development and have indicated the waste if this potential is neglected. It is now up to others to ensure that the future is one of development and not

neglect. It is up to everyone concerned with services to mentally handicapped people to pick up and build on the work that all the delegates put into 'Listen' and to do them justice and show that something lasting was achieved at the conference' (Ibid., pp34).

Delegates also shared these concerns (see Ibid.). However, scepticism was expressed with regard to staff reactions in hospitals ('The staff won't do anything like that... every time you do it [speak out] they don't like it'), and in hostels ('I wouldn't bet on it... Very few speak ... people don't want to listen'). Furthermore, many delegates felt that the one-off nature of the CMH conferences was inadequate: 'we should have a meeting once a month'.

Fortunately, CMH's American links culminating in Paul Williams and Bonnie Shoultz co-writing the book *We Can Speak for Ourselves*, reviewing international developments (Williams and Shoultz 1982). This highlighted the variety of groups that were taking off in the UK and the USA, fitting the United Nations Declaration of the Rights of Human Persons (1975, cited in Oliver and Campbell 1996, p19), which asserted that:

'Organisations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons' (Section 3447.12).

Groups continued to grow in dance companies, sport and recreational clubs, through to Adult Training Centres and hospitals, groups were growing. According to Hersov (1996), in the UK, two of these set-ups, the MENCAP London Division's Participation Forum and City Lit, grew in stature in the early eighties (reflecting strong financial support gained through charity

funds). In 1984, they sent representatives to the 'First International Self-advocacy Leadership Conference' in Tacoma, North America (see O'Brien 1985 for conference report). By this time the movement had grown markedly in the US, with the *People First* organisation holding its first convention for North American members as early as 1974 (Dybwad 1996). By 1975 there were 16 *People First* chapters formed in 12 cities (Crawley 1982). According to O'Brien and Sang (1984) the links between English and American self-advocates continued to be productive.

Things start to take off

At the 'First International *People First* Conference' in 1984, a number of English delegates were inspired to set-up *People First of London and Thames*. This self-advocacy group was independent of a service base, with members attending voluntarily, and by 1997 had a number of paid independent supporters. It has been one of the most influential collectives within the movement (Hersov 1996). 1988 was another significant year for UK self-advocates. First, the 'Second International *People First* Conference' was held in Twickenham, entitled 'A Voice of Our Own - Now and in the Future' (Wertheimer 1989). In 1993, the 'Third International Conference' took place in Toronto Canada, with many UK *People First* groups attending. The fourth is to be held in Alaska in 1998.

While the UK movement has grown in strength internationally, it has also made some links with the larger disability movement in the UK. Hersov (1996) records how the well-known self-advocate Gary Boulet represented *London People First* on the 1992 national council of the British Council of Organisations of Disabled People as it was then known (now the British

Council of Disabled People, BCODP). More recently Simone Aspis, previously Campaigns Officer at *People First London*, has maintained links with the BCODP, and was the self-advocacy movement's only representative in Campbell and Oliver's (1996) account of the British Disability movement. Moreover, self-advocates have become involved in formal studies of services (see Whittaker, Gardner and Kershaw 1991, Downer and Fearns 1993, *London People First* publications), appeared on TV, in the broadsheets and taken part in civil rights demonstrations:

> 'In the last decade, there have been important landmarks in the growth of self-advocacy throughout the country ... There is every reason to believe that the [movement] ... will continue to gain new members and widespread support, and that it will reach even greater heights in the future' (Hersov 1996, p139).

Diversity grows in the movement

For some the *People First* movement is the self-advocacy movement (see for example Dybwad and Bersani 1996). However, the foundations of the British movement are not found solely in *People First* (nor the London groups focused on by commentators like Hersov). The movement's origins can be traced back not only to 'independent' (*People First*) groups but also to the growth of *trainee committees* in Adult Training Centres, Social Education Centres and hospitals over the last three decades. Crawley's thesis in 1982, and her 1988 survey of trainee committees, documented the rush of self-advocacy issues into Centre curricula (Crawley 1982, 1988). Similarly, Paul Williams' (1982) paper on 'participation and self-advocacy'

reflected some small-scale translation of self-advocacy issues into service decision-making (participation). He argued:

'Handicapped people have a lifetime of experience of being controlled and dominated by others. They are denied experiences of equality with others and control over their own affairs... Participation seeks to provide handicapped people and others with experiences of equality and sharing. Self-advocacy enables handicapped people to take their own decisions and exercise control over their own affairs' (p3).

The doing of self-advocacy in service bases fits 'user participation' and community care rhetoric in government policy (Menolascino and Eaton 1980)[2]. In 1991, the Health Minister Virginia Bottomley observed that:

'The challenge is to ensure that we provide a seamless service based entirely around the needs and wishes of the users of care and their carers' (HMSO 1991).

As learning difficulties services experience a transition from public sector organisations to private sector management, and a shift from residential to community bases, self-advocacy appeals to those promoting service innovation (Braddock 1994). For Crawley (1982, p78) where *People First* has succeeded through its independent organisation, formality and the impetus of members, the medium of service-based collectives has merged

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[2] see for example *Community Care in the Next Decade and Beyond: Policy Guidelines* (HMSO 1990).

self-advocacy with user empowerment initiatives promoted by community care policies. She cites, for example, the work of the AVRO Centre in Southend, Essex. In 1981, they campaigned to change the term 'trainee' to 'student' and rallied against the 25pence per day Centre charges, gaining publicity in *The Guardian* later that year (November 30 1981). Here then is another side to the movement:

'The rapid growth of the number of committees in the last few years, and the spontaneous nature of this development, is indicative of an awakening to the need to consult with the 'consumer' of the services that Adult Training Centres provide' (Crawley 1982, p94).

Furthermore, the diversity within the self-advocacy movement has intensified through the input of *citizen advocacy* schemes (Wolfensberger 1972a, Flynn and Ward 1991, Hampson 1994). Advocacy constitutes a new helping relationship (Biklen 1976). Smiley and Craik (1972) describe a program initiated by social workers that located and screened citizen advocates to act as big brother, friend, social worker and legal counsellor to people with learning difficulties. Taken further, Schapiro (1976) reports on a program where 20 senior citizens were paid to support de-institutionalised adults. An increase in the adults' capabilities for independent living was reported. While many individual advocacy relationships appear to have developed in line with the demands of the 1981 United Nations Declaration of Rights of the Mentally Handicapped, the impact of citizen advocacy upon the self-advocacy movement is yet to be understood (Flynn and Ward 1991). In 1979, Herr recognised that advocacy was necessary in championing the legal rights of the mentally retarded (Herr 1979). However, there are concerns that if citizen advocacy remains accountable to

service systems then its impact upon self-advocacy, both individual and collectively, will be stifling rather than empowering (Flynn and Ward 1991, Tyne 1994). For Daniels (1982, p25), the move from parent and professional advocacy to self-advocacy mirrors the developmental task of growing up and marks the recognition that people with learning difficulties are persons with their own voice. Gilbert and Specht (1976) found that professionals saw citizen advocacy as undermining their professional ethics and the interests of their clients, while both Ross (1972) and Wise (1973) recognise that the relationship between professionalism, advocacy and self-advocacy are marred by struggles. Finally, Mitchell (1998) notes the influence of *family advocacy groups* upon the development of self-advocacy. It would appear that the self-advocacy movement is complicated.

A new social movement?

In 1992, Simons estimated that there were more than 500 self-advocacy groups in the UK. The movement's diverse nature suggests that self-advocacy has developed, branched off and grown in a multitude of ways. As a consequence of these developments, Bersani (1996, pp265-266) argues with reference to Shakespeare's (1993b) commentary that the self-advocacy movement now comprises a *new social movement*, characterised by a number of processes shown below. However, questions still abound:

• *Members go beyond typical roles* - here people with learning difficulties, 'self-advocates', transcend typical positions of client, trainee, patient and user. Some have striven to change their own and others lives, some will be representatives of their peers in Centres, others will be paid advocates as part of citizen advocacy initiatives.

However, exactly how do others without learning difficulties support or stifle the transition to the role of self-advocate?

- *Representation of a strong ideological change* - a change from the term mental handicap to learning difficulties and the development of independent self-advocacy groups free from parental and professional organisations, can be seen as indicative of change. There have also been more general demands for ideological change: 'We believe that people with disabilities should be treated as equals. That means that people should be given the same decisions, choices, rights, responsibilities and chances to speak up to empower themselves as well as to make new friendships and renew old friendships just like everyone else. (*Self-advocates Becoming Empowered organisation*, USA, paraphrased by Kennedy 1997, p1). Meanwhile, self-advocacy in service settings calls into question client-staff relationships and the professional ethos (Crawley 1982). Yet, how are societal structures, professional practices and political understandings implicated in this move away from 'retardate' to 'self-advocate'?

- *Emergence of a new identity, often drawing upon a characteristic formerly seen as weakness* - slogans such as 'disabled and proud', 'label jars not people' (used by *People First)*, along with 'rights not charity' and 'piss on pity' (appropriated from the larger disability movement), may be seen as reflecting a new found, more positive, identity. Nevertheless, are new identities resistant to dominant discourses which, for example, position people in terms of their purported 'handicaps'?

- *Relationship between the individual and movement is blurred* - and apparent in the definitions of self-advocacy offered by self-advocates presented above. Individual and collective self-advocacy often appear to be inseparable. Even so, is the movement, the formal group context and the support of others that important to individual self-advocates life experiences?

While self-advocacy may appear to constitute a new collective movement, recognised by others with learning difficulties, delving further into the literature it would appear that below the surface things are more problematic. Typical of previous examinations, Bersani's (1996) above analysis focuses predominantly on *People First* groups. As noted above, the movement is actually made up of many factions (Browning, Thorin and Rhoades 1984, Bramley and Elkins 1988, Crawley 1988). However, some observers have argued that any deviation from the *People First* group poses a threat to the very doing of self-advocacy. These observations are considered in the following section.

The components of a self-advocacy group

Now to dig deeper into this 'new social movement'. Much of the literature that has explored self-advocacy has done so with reference to the self-advocacy group (Hanna 1978, Siegel and Kantor 1982, Williams 1982, Williams and Shoultz 1982, McKenna 1986, Worrel 1987, 1988, Crawley 1990, Brooks 1991, Simons 1992, Sutcliffe and Simons 1993, Hampson 1994, Shoultz 1997a, 1997b, 1997c, Dowson and Whittaker 1993).

Observers have focused on contexts where self-advocacy can be seen as formally taking place:

'When many people think of self-advocacy, they think in terms of self-advocacy groups and the activities of their members. Although this perspective does not exclude the idea of individual self-advocacy, it focuses primarily on people who have consciously decided to 'speak out' or who associate themselves with groups that have taken up that standard. Hence it is possible to talk in terms of a broad movement that falls squarely in the self-help group tradition, and has strong parallels with other alliances (for example the British Coalition of Disabled People and Survivors Speak Out)' (Sutcliffe and Simons 1993, p36).

The next section reviews literature to examine the composition of groups and the reasoning that is employed to justify a number structural and organisational forms. In addition, controversies associated with group components and typology will be presented.

What is a self-advocacy group?

Speak for Ourselves of Newcastle have produced a video called 'Start! - How to set up and run a successful self-advocacy group' (1993). *Speak for Ourselves* function independently of service, advocacy and parental agencies. Members come along voluntarily, supporters have no service ties and activities are financed by money from voluntary organisations (and the sale of their video). Group members with learning difficulties (self-advocates) and people without learning difficulties that support the group

(supporters or advisors) front the video. Typically, *Speak for Ourselves* get together for a meeting, in their case weekly. At the meeting, a chairperson (a self-advocate) is responsible for keeping the group in order and bringing in people who have something to say. Often topics of discussion are decided at the start of the meeting, which are returned to later, although members are encouraged to speak up freely. Experiences, good and bad are divulged, opinions are shared and in some cases action is taken by the group for and with members. *Speak for Ourselves* argue in the video that self-advocates themselves can and should be involved as far as possible in the setting up of their *own* groups. They offer a number of steps to follow :

- *Get people interested* - tell Centre users, hostel flat-mates and work colleagues what they will get out of being in the group, either by word of mouth, leaflets or by posters.

- *Find a meeting place* - someone's house or a Community Centre make ideal settings, while ATC could be used if no where else is available.

- *Organise transport* - so members can get to meetings. This is helped when a self-advocate takes on the role of 'transport officer'.

- *Find an advisor* - this is a person (usually without learning difficulties) who helps the group, 'Someone who gives support especially in the early days', but who, *'Shouldn't* run your group but help *you* to run it'. *Speak for Ourselves* suggest getting in touch with the Council for Voluntary Services. It is as they say, 'Better to find someone who doesn't work at the Day Centre'. Later, 'You will have to decide if your advisor is to paid or volunteer'.

- *Elect a committee* - officers mentioned include chairperson, secretary, treasurer and transport officer. Officers may be chosen on a nomination and election basis or members may take-turns in the various positions.

- *Raise money* - through sources such as charitable trusts, health authorities and local councils or payment maybe accrued if self-advocates help train people who work with people with learning difficulties.

- *Make the group aware of what it can do* - members of *Speak for Ourselves* give their own experiences, 'Talking about improving services, write letters to the council, plan conferences, invite guests, right to get engaged, have a boyfriend and get married, have parties and discos'.

Speak for Ourselves represent one way of doing self-advocacy, and as will be shown below, one *type* of group. Consequently, a number of specific points come out of the video. First, self-advocates themselves are the significant parties. Right from the start, and in activities from then on, the group is centred on the interests of the members. Second, interested people are required. A voluntary basis to group membership is prescribed, with self-advocates themselves determining their own group membership. Finally, the need for clarity by the advisor of his / her role is argued for, mirroring Paul Williams argument:

> 'Most groups have an advisor. This person is there to help when, and only when, required; the advisor is not in control of the group' (Williams 1982, p3).

However, while *Speak for Ourselves of Newcastle* have a clear outline of how their group is run, other groups in the movement run along very different lines. While the basic components of advisors and self-advocates

remain, ways of organising self-advocacy take a number of forms (Bramley and Elkins 1988).

Different types of self-advocacy and associated controversies

People First of Washington State have described four models or 'types' of self-advocacy group that exist in the movement. This typology has been employed in a number of studies (see for example Crawley 1982, 1988, 1990, McKenna 1986, Simons 1992, Dowson and Whittaker 1993). The pros and cons of each type are presented below.

(1) The 'autonomous' or 'ideal' model

E.g. People First, Speak for Ourselves of Newcastle.

Advantages	These groups are independent in terms of time, organisation and finance from professional services or parent bodies
	Advisors are independent of services
	Group members are free from 'conflicts of interest' with professionals or parents, so can feel free to voice opinions without fear of embarrassment or recrimination
Disadvantages	Groups must support themselves from the beginning
	Financial struggles and lack of resources are a problem.

(2) The 'divisional' model

Arises out of existing parent or professional organisations for people with learning difficulties e.g. MENCAP executive committees, Advocacy organisations.

Advantages

There is easy access to a range of resources (meeting places, money, administrative support)

Advisors can be well-trained in advocacy skills

Disadvantages

Potential 'conflict of interests' can occur between the demands of self-advocates and those of parents and professionals

Risks of self-advocates being over-powered and relegated to a back-seat are ever-present as the concerns of the organisation take precedence

(3) The 'coalition' model

Arises out of a larger group for disabled people (or other minority group) e.g. Independent Living organisation, Council of disabled people, community initiative

Advantages

Self-advocacy along with other disabled people increases the strength of the group and makes links with the larger disability movement. A strong and positive disabled identity is encouraged

Advisors can be well-trained and disabled

Adds legitimacy, increases political power and improves ability to generate funding.

Disadvantages   Risk of being over-powered and relegated to a backseat as more articulate and politically strong disabled members take over.

(4) The 'service-system' model

Self-advocacy group located in a service delivery system e.g. Trainee committee in ATC, SEC, patients forum in hospital, residents panel at group home.

Advantages   No need to recruit members as a meeting place is instantly provided.

                             Transport problems are minimal as are access to a range of resources and provisions.

Disadvantages   Constant threat of 'conflicts of interest' between self-advocates and service if group challenges service system

                             May be nothing more than an extension of existing training activities and becomes a token gesture rather than 'real' self-advocacy.

In the literature the 'ideal' autonomous group type is generally regarded as potentially the most empowering (see for example Hanna 1978, Daniels 1982, Worrel 1987, 1988, Crawley 1990, Dowson and Whittaker 1993, *Speak for Ourselves of Newcastle* 1993, Tyne 1994, *People First Liverpool* undated, *Huddersfield People First* undated). By contrast, the service-system model has received the most damning criticism. For Bill Worrel (1987, p30) self-advocacy is a growing force and an essential part of this process is learning to be an independent organisation. When service systems get involved with self-advocacy the ability of a group to promote self-determination is threatened (Worrel 1988). As a high profile self-advocate in Canada, Pat Worth, puts it:

'Being involved on a one-to-one basis with people with handicaps, as *People First* is, helps to deal with the issues directly. Associations delivering services may find this difficult to achieve' (Quoted in Yarmol 1987, p28).

Tyne (1994, p250) argues that service-based sponsorship of (self)advocacy limits and sometimes subverts it altogether. For Downer and Ferns (1993, pp145-146), a contradiction emerges. They argue that while positive steps must be taken to make sure that self-advocacy happens in residential and day-care establishments, they also see a need to help people set up groups without taking them over and making them part of services. For Hanna (1978), Worrel (1987, 1988) and Crawley (1982, 1990), to understand the paradox of service-based self-advocacy, and the potential of autonomous groups such as *People First*, we need only to look at the roles of those who support self-advocates.

The advisor role and controversies

In examining group structure, previous literature has tended to deal with the role of the advisor (Hanna 1978, Worrel 1987, 1988, Clare 1990, Sutcliffe 1990, Sutcliffe and Simons 1993, Simons 1992, Dowson and Whittaker 1993). Going back to what *Speak for Ourselves of Newcastle* (1993) have to say, the advisor should be, 'Someone who gives support especially in the early days', but who, *'Shouldn't* run your group but help *you* to run it'. They go further to suggest that it is better to find someone who doesn't work at the Day Centre, and later the group, 'Will have to decide if your advisor is to paid or volunteer'. As Barnes and Wistow (1992c, p94)

acknowledge, for many people who have had little experience of being able to exercise control over their own lives, learning to participate in comparatively safe environments may be an important first step. This is where the advisor comes in:

'Once you have shown that you respect the members as equal human beings, that you're not like the rest of society, you have built the basis for a strong working relationship with the group' (Worrel 1988, p55).

Dowson and Whittaker (1993, pp44-47) forewarn advisors to be clear about their roles - to be honest about doubts they may have inside the group, to express opinions, but clarify that they are opinions not facts - 'Be a supporter not a spokesperson - don't take on others' responsibilities'. The first step in understanding the advisor role is to understand the members. This awareness leads to another key point - that the advisor may need to withdraw when the group wants it, when he or she is not needed, or when someone else would do better in the job. The advisor should aim to work him or herself out of a job (Dowson and Whittaker 1993, p44).

Ideally a reciprocal relationship forms. As the group increases in autonomy then the advisor's input decreases proportionally. Many self-advocates have urged advisors to keep this relationship in mind. As *Capitol People First of Sacramento, California* demand: 'we need teachers not keepers' (Quoted in Booth and Booth 1992, p67). Advisors are important but not always needed (Worrel 1988, p73):

'Maybe in the future there will be no need for advisors. Our goal should be that as a group develops the skills and the links with the community, to be able to use the many advisors in the community that we all use in our lives' (Ibid.).

For Worrel (1988, p35) all advisors should be asking themselves how they *use* their power in ways that empower or disempower members. Similarly, Hanna (1978, p32) asserts that:

'There is an underlying philosophy that anyone who wants to become an advisor to a *People First* organisation must embrace. The philosophy is consistent with the goals and purposes of the organisation, 'that people are people, no matter what their abilities or limitations might be' ... they may have limitations but everyone has limitations of one sort or another'.

Previous literature has identified a number of controversies associated with the *status of advisors*. For example, when advisors are staff or professionals, particularly in service systems, problems arise. For Clare (1990), there is an undeniable paradox in professionally led self-advocacy. Staff members of service systems are necessarily located in positions of power (Oliver 1990, 1993, 1996). Their descriptions, assessments and evaluations, as well as their knowledge of available opportunities are called upon to determine the course of a disabled person's life:

'Their professional identity, and certainly their professional accreditation, will be based on their control of knowledge about disability' (Clare 1990 p24).

Consequently, staff-advisors are placed in a seemingly impossible role (Hanna 1978, p31). While their existence is testimony to the fact that many professionals were instrumental in supporting early self-advocacy set-ups (Crawley 1982, Worrel 1987, p31), their impossible position may be largely put down to a conflict of interests. Conflicting motivations between facilitating self-advocates' independence and maintaining service goals is a common and underlying dilemma of professional advisors in service-based groups. For Worrel (1987, p35, also see 1988, p38) groups that avoid controversy often have advisors who are affiliated with service organisations. In these groups, supporting members is hindered by rules of operation such as: 'Don't bring your problems to the meetings'. This may be translated into:

> 'Don't rock the boat by raising real problems in your life that the members of the group might identify with. We may have a revolt on our hands!' (Worrel 1987, p35).

Sutcliffe (1990, p27) elaborates on this point. If groups are to provide an independent voice, then being advised by staff members whose loyalties are split, may seriously undermine the development of self-advocacy. Members may be intimidated by the advisor's accountability to the services they use, and may feel uneasy complaining about the services that they are offered:

> 'A conflict of interest occurs when the advisor is paid by the agency that serves the members. If a group wants to criticise the way the workshop is run, the advisor may have trouble supporting the group while being a staff person at the workshop' (Worrel 1988, p38).

For Williams (1982, p4), self-advocacy is not simply fun, sport or entertainment, it has a serious purpose. However, groups that meet as part of the week's programme in a SEC or ATC may soon resemble another activity implemented by staff and the potentially radical impact of groups upon members' lives is lost. Moreover, for advisors to work themselves out of a job seems impractical when that support is part of the working week. It would seem that that the general principle of 'letting go' directly opposes the very philosophy of professional intervention (Barker and Peck 1987, p28 cited in Flynn and Ward 1991, p132). The answer to these problems, then, is the 'ideal autonomous' group, where advisors are free from service accountability and the group can progress without a conflict of interests (Hanna 1978, Williams 1982, Williams and Shoultz 1982, McKenna 1986, Worrel 1987, 1988, Crawley 1990, Flynn and Ward 1991, Simons 1992, Downer and Ferns 1993, Sutcliffe and Simons 1993, Hampson 1994, Shoultz 1997a, 1997b, 1997c, Dowson and Whittaker 1993, Mitchell 1998).

Scrutiny of the typology and advisor roles presented in the literature above ensures that types of self-advocacy other than the autonomous group type, supported by the independent advisor (*People First*), are given short thrift if not rejected altogether. Yet, to adopt this rejection of certain group types would appear to make an appraisal of self-advocacy highly selective and ignore the prevalence, and influence, of other group types. Therefore, the following section outlines questions that are raised by the literature review.

Questions about self-advocacy – where does this leave us?

Three broad questions emerge from the literature review. First, what is the nature of the contemporary self-advocacy movement? Second, how do self-advocacy groups impact upon the lives of people with learning difficulties? Third, how do self-advocacy groups work?

What is the nature of the contemporary self-advocacy movement?

The typology literature presented above suggests that self-advocacy is not synonymous with *People First*. As Crawley (1982, 1988) observed, the spread of self-advocacy groups in Centres constitutes a large part of the growth of the movement. Recently, as Flynn and Ward (1991) and Tyne (1994) recognise, the input of citizen advocacy constitutes another development. Moreover, there may be contradictions inherent within *People First* groups. For example, a group that is financially independent of services, but which has staff advisors who come into the group in their own time, problematises understandings of 'good' and 'bad' self-advocacy presented in the literature above. This thesis aims to describe variations and complexities within the movement.

How do self-advocacy groups impact upon the lives of people with learning difficulties?

Carabello and Siegel (1996, p238) ask: who are the leaders in the movement, whom do they represent and are they people with disabilities? A turn to the perspectives of self-advocates would uncover what members gain from groups. As Worrel (1988, p78) asserts:

'We have to try to look at life through the eyes of the person who has been labelled, understand what it means to be labelled, and why self-advocacy is important'.

When Safilios-Rothschild (1981, p11) argued that the reluctance of professionals to relinquish extensive power and control over their clients is something that cannot easily be broken, she was unable to forsee the challenges that were to be posed by disabled people and their organisations (Brisenden 1989, p218). Indeed, the significance of the role of non-disabled people in self-advocacy groups has been questioned:

'The most well-meaning, helpful, sensitive and committed advisor will never be able to do the job of empowerment as effectively as a well-prepared, well-trained self-advocate' (Worrel 1988, p13)

For Fairclough (1989, 1992), Ferguson, Ferguson and Taylor (1992a, b, c), Goode (1992), Ferguson and Ferguson (1995) and Skrtic (1995a, b, c), the very resilience of disabled people has ensured that they themselves have, historically, been self-organising. Self-advocacy is nothing new but listening is (Crawley 1988, p47). This thesis will attempt to uncover some of the links between self-advocacy group membership and life experiences.

How do self-advocacy groups work?

There appears to be a tendency in the literature to sweep under the carpet certain group types or advisor roles because they epitomise 'bad self-advocacy'. It remains to be seen whether or not groups other than *People*

First are any good, or for that matter, that bad (Crawley 1988, Sutcliffe and Simons 1993). After all, as Worrel (1988, p40) recognises, most advisors today are faced with conflict of interests and the first essential step for advisors is to be sensitive to this issue of power. If some groups do provide 'real' opportunities for self-advocacy (Crawley 1988), as the literature suggests, then in what ways do they provide these 'real' opportunities (and indeed what is 'real')? Do types of group and status of advisors so causally relate to the promotion or relegation of self-advocacy as suggested by previous literature? Or are other group processes influential? This thesis will attempt to examine further the organisation of groups and dynamics of self-advocacy.

A contemporary appraisal

As Crawley (1988, p47) recognises, we cannot assume that the increase in the frequency of so-called self-advocacy groups directly relates to an increase in opportunities for meaningful self-advocacy. Previous literature reviewed above has pointed to many dilemmas in the self-advocacy movement. As we enter the decade of the citizen (Dahrendorf 1990) how are people with learning difficulties fairing? A contemporary appraisal of self-advocacy seems timely.

The need for a contemporary appraisal

'Thus far there has been little independent evaluation of citizen, professional and group advocacy for their respective or collective effects upon service users ... sufficient to indicate the best way forward at the present time' (Grant 1992, p75).

Self-advocacy has been recognised as a 'new' political activity with the potential to challenge disabling society (Browning, Thorin and Rhoades 1984). The need for a contemporary appraisal is observable in light of self-advocacy's diversity and the literature's deficiency in accounting for recent developments in groups, individuals and 'the movement' (Miller and Keys 1996). A multitude of philosophies and practices exist. What this means to self-advocates is yet to be extensively assessed. As self-advocacy has grown and developed, its relationship to the empowerment of people with learning difficulties becomes increasingly opaque. This study will appraise self-advocacy in the lives of people with learning difficulties by posing three questions. First, what is the nature of the contemporary self-advocacy movement? Second, how do self-advocacy groups impact upon the lives of people with learning difficulties? Third, how do self-advocacy groups work? These questions will be approached with a particular theoretical perspective in mind. This perspective is considered in the next chapter.

Chapter 3

Self-advocacy, impairment and the social model of disability

Introduction

'It means no one will hire me on a job unless they hear from a rehab counsellor or social worker. Get what I mean when I say it's hard for handicapped people to find a job?' (Larry on what learning difficulties means in Langness and Turner 1986, p71).

'The reintegration of individuals is currently largely determined by others who have power ... there is only one guaranteed way to regain our power and therefore control of our own lives ... That way is through self-advocacy and self-help' (Lawson 1991, p69).

This chapter introduces an 'inclusive' social model of disability, the perspective that guides this thesis. It is argued that an awareness of the socio-historical, cultural and political bases of disability is a pre-requisite for an appraisal of self-advocacy. The individual and social models of disability will be presented. Then, links will be made between the social model and literature that considers learning difficulties as a social construction. Finally, it is concluded that an appraisal of self-advocacy grounded in the experiences, stories and actions of people with learning difficulties will draw upon, and in some small way build upon, an inclusive social model of disability.

Perspectives on disability - Individual and social models

This chapter introduces the theoretical model that underpins the appraisal of self-advocacy in this thesis. First, the individual model of disability is presented. It is argued that this model reflects dominant understandings of disability that are held in society. Any appraisal that is theoretically underpinned by this model would undermine the self-advocacy of people with learning difficulties. Second, the social model of disability is presented. This model has been put forward as an alternative way of understanding disability that holds the self-empowerment of disabled people at its core. The model is a theoretical ally to the actions of disabled activists. Third, to ensure that the social model of disability recognises the self-advocacy of people with learning difficulties, it is argued that the model benefits from the inclusion of literature that views learning difficulties as a social construction. This 'inclusive' social model of disability provides a theoretical framework that embraces the self-advocacy of self-advocates whilst being sensitive to the impact of disabling society. This inclusive model theoretically underpins the appraisal of self-advocacy in this thesis.

(1) 'The tragic person with disabilities' - An individual model of disability

'The word 'retarded' is a word. What it does is put people in a class ... There's always going to be people who are going to hold it to the ground. We're on one side of the wall and the stone throwers are on the other side' (Ed Murphy cited in Bogdan and Taylor 1982, p77).

The stone throwers

From the mid-17th century onwards, one of the major projects of modernity was being realised. The victory of scientific rationality over expressions of the divine purpose (Kumar 1978), further enforced humanity's search for technological supremacy and control over nature (Branson and Miller 1989). Intellectual and societal progress went hand in hand and the immature academic paradigms of the social sciences blossomed. Around the start of the 20th century, dominant understandings of society's 'defectives' were influenced by the work of Charles Darwin. His 1859 book, 'On the Origins of Species', was seen by many as an indicator of how far scientific understanding had progressed (Barnes 1991). By providing a direct relationship between human beings and other animals, with terminology denoting survival of the fittest and natural selection, Darwin's theories of evolution fitted the scientific project of modernity (Turner 1990). Consequently, earlier concepts of idiocy, previously located within the realms of religion were now positioned within a scientific Darwinian framework. Crudely, as Hunt (1993) puts it, idiocy was transformed. Mental deficiency was attributed to genetic mutation - the unfortunate result of inappropriate breeding on the part of defective parents (Sarason and Doris 1969). The views of an eminent theorist around this period highlight the impact of Darwinism on intellectual thought:

'The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs... they cause unutterable sorrow at home and are a menace and danger to the community. Feeble-minded women are almost invariably immoral, and if at large usually become carriers of venereal disease or give birth to children

who are defective as themselves... every feeble-minded person, especially the high-grade imbecile, is a potential criminal... the unrecognised imbecile is a most dangerous element in the community' (Fernald 1912, lecture given to the Massachusetts Medical Society, quoted in Sarason and Doris 1969).

Societal hopes for the prevention of such individual defects soon became immersed within celebrated notions of *Social Darwinism*[1] (Barnes 1991). A rational and powerful ideology was provided where the control of 'mental defectives' could be efficiently devised (Fido and Potts 1989). According to Barnes (1991), the perceived scientific authenticity provided by frameworks of understanding such as Darwinism appealed to a society dominated by a relatively small elite of property owning individuals, who welcomed any opportunity to justify their newly-acquired wealth, status and power. 'It was quickly adapted from the biological domain to apply to human societies' (Ibid., p19). The implications of this grounding of scientific and socio-political concerns were devastating. Social Darwinists were instrumental in forming the eugenics movement. One proponent of eugenics, a 'founding father' of psychology (Hunt 1993), Francis Galton (Darwin's cousin) argued:

'Eugenics is the science of improving stock, which ... takes cognisance of all influences that tend in however remote a degree to give to the

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[1] Social Darwinism is chosen from a multitude of philosophies to show the historical origins of learning difficulties and subsequent social-cultural reactions. Other philosophical and institutional beliefs implicated in society's treatment of people with learning difficulties include religious and moral tensions, medicalisation, the rise of psychological assessment and Foucauldian considerations of 'the body'. For a comprehensive historical overview see Wright, D., and Digby, A. (1996). *From Idiocy to Mental Deficiency : Historical Perspectives on People with Learning Disabilities*. London: Routledge.

more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had' (Galton 1869 cited in Hunt 1993).

The eugenics movement advocated selective breeding from one generation to another and expected a subsequent increase in the proportion of people with better than average hereditary endowments (Taylor and Bogdan 1992). The 1903 American Breeders Association championed numerous policies concerning the regulation of particular individuals' rights to conception (Stratford 1991). In turn, institutionalisation provided an effective way of separating defective people from society thus reducing breeding opportunities. Sterilisation was addressed as an additional remedy, with the first mandatory sterilisation law being passed in the USA in 1907 (Ibid.). The logical conclusion of the eugenics movement was realised with the rise of fascism in the 1930s and the extermination of more than 300,000 'mental defectives' (Wolfensberger 1981).

In 1946 an ex-member of the British Eugenics Society, who had worked for six years with the 'feeble-minded', concluded that such labelled people:

'Show such a variety of virtues - generosity, altruism, good will, sweet temper - that I began to think that a world peopled by mental defectives might be an improvement on the present one' (from Eugenics, p115 cited in Morris 1969, pxix).

Townsend (1969) and Lawson (1991) observe that eugenic beliefs had been discredited for a number of reasons by the 1950s. First, it became more and more obvious that genetic variation was far more complex than had originally

been thought, with *social factors* being implicated in understandings of subnormality. Second, the anticipation that a residue of 'feeble-minded' within the population would lead to national degeneracy had not occurred. Third, the formation of an 'unholy alliance' between governments' commitment to decreasing public expenditure, and an increasing body of literature denouncing institutionalisation, prompted moves towards intensive deinstitutionalisation (Banton, Clifford, Lousada and Rosenthal 1985). However, old ideas such as Social Darwinism take a long time to die (Wright and Digby 1996).

Foucault's (1970, 1975) conception of 'genealogy' is useful here. Knowledge, archaic, ridiculous, unbelievable as it may be, can become buried and disguised in what is considered rational, common sense or 'the truth':

> 'Truths are illusions of which one has forgotten that they are illusions, worn out metaphors' (Hekman 1990, p27).

As Jenkins (1993, p18) argues, ubiquitous taken-for-granted concepts of normality do two things at once: they describe as normal those human characteristics which are most typical and then assert that they are the way things ought to be. For Brechin and Walmsley (1989, p9), the scandals of the 'institutionalised years' can so easily be repeated if care is not taken to prevent them. Even in the 'humanitarian' epoch of community care, institutionalisation exists as the only option available to some people with learning difficulties (Potts and Fido 1991). Ferguson (1987, p51) observed that in America alone, over 125, 000 people with labels of retardation remained incarcerated in large, segregated public institutions. In the UK the OPCS surveys showed that 422, 000 disabled people, 20 percent of whom

were below retirement age, still lived in 'communal establishments' or institutions (Martin, Meltzer and Eilliot 1989). Beliefs, whether they are about biological inferiority or segregation of 'defectives', burrow themselves into contemporary rhetoric and practice:

> 'Many of the fundamental attitudes and prejudices which led originally to the establishment of colonies remain virtually untouched. Assessment and classification still abound. So too does arbitrary removal from home, whether this home is with the family or friends or is a group home, hostel or hospital ... Just as the inmates were forced to fit into the colony, so today people have to accommodate to available places. If they do not fit in or object to their placement, the label of 'problem behaviour' is likely to be applied' (Potts and Fido 1991, p133).

Like it or not, we are heirs to past attitudes, beliefs and current practices (Stratford 1991, p5). Old structures and vocabularies persist (Taylor and Bogdan 1992, p85) and practices which appear to be universal and common-sensical can often be shown to originate in the dominant class or dominant bloc, and to have become naturalised (Fairclough 1989, p33):

> 'Most definitions we use to interpret the world are learned from others and are sufficiently imbedded in the cultural heritage to make it difficult to extract and objectify them for analysis' (Mercer 1973, p1).

To find out what these beliefs are, Parker, Georgaca, Harper, McLaughlin and Stowell-Smith (1995) along with Fairclough (1989), assert that the common-sensical must be rendered strange. Over the last thirty years, a

proliferation of writings has done exactly this: rendered every-day understandings of disability as strange.

Defining the past

Oliver (1990, following the UPIAS's 1976 'Fundamental Principles' document, see below) was one of the first (disabled) writers to label dominant common-sense understandings of disability[2]. These, he asserts, reflect an **individual model of disability** or Personal Tragedy Perspective. For Barnes (1991), in these dominant discourses lie Social Darwinism, the medicalisation of disability and assumptions of pathology associated with impairment. Consequently, for Shakespeare and Watson (1997), well-regarded 'professional' and 'expertly' defined models of disability are steeped in the characteristics of the individual model. The World Health Organisation's (WHO 1992) definition of disability is a good example:

'Disability is the *effects of* the impairment on everyday activities' (My italics).

For learning difficulties, The West Midlands Regional Health Authority's definition (1993, pp 60), shows similarities with WHO's:

'A learning disability is an impairment of intellectual functions, which occurs before adulthood and *results in* significant disabilities in day to day life' (My italics, cited in Ford 1996, pp57).

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[2] Berger and Luckman (1967) term these common-sense understandings 'appendages of knowledge'.

Finally, the 1995 Disability Discrimination Act reifies the individual model when it defines disability as:

'Either a physical or mental impairment, which has a substantial and long-term adverse affect on a person's ability to carry out normal day-to-day activities' (HMSO 1995, section.1.1).

These definitions say something very simple - that impairment, whether it be physical or 'of mind' results in and creates disability. Hence impairment and disability are synonymous, inseparable concepts. Following this, 'impaired thought' *leads to* a myriad of disabilities - disabled thought, disabled learning, disabled interactions with others, disabled personal relationships, disabled sex lives and disabled parenting[3]. The emerging image of the person with learning difficulties or physical impairment, then, is not one of autonomy but of a loss of wholeness - a personal tragedy that renders the individual the focus of professional intervention (Morris 1991, 1993b). Barnes (1990) argues that this results in disabled people being assigned a position in a **culture of dependence**. Their social ineptitude, reified by the dominant discourse, renders them as burdens to their families and to society at large (Lefley and Johnson 1990). They are conceptualised as any other minority group and treated and reacted to as a category rather than as people (Brechin, Liddiard and Swain 1981). They represent a challenge, a problem at the level of everyday intercourse (Thomas 1982). As the antithesis of the norms disabled people no longer represent the collective values of the

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[3] See Oliver, undated, *'Politics and Language'* for overview, Chadwick 1995 for an evaluation of the implications of the DDA and Walmsley 1991 for discussion about definitions of learning difficulties.

status quo (Morris 1991), delineated by prevailing cultural politics (Corbett 1991).

The incongruent relationship between self-advocacy and the individual model

Prior to Oliver's (1990) identification of the individual model, Abberley (1987, p18) suggested that an individualised concept of disability:

> 'By presenting disadvantage as the consequence of a naturalised 'impairment' ... legitimates the failure of welfare facilities and the distribution system in general to provide for social needs, that is, it interprets the effects of social mal-distribution as the consequence of individual deficiency'.

In light of the literature in the previous chapter it is difficult to see how self-advocacy, empowerment and self-determination of disabled people can be formed upon understandings of disability that assume individual inability (Finkelstein and Stuart 1996). Indeed, Morris (1991) observes that when disabled people step out of the passive role assigned by society, and take up active roles of *activist* (or self-advocate), disabling culture is unable to deal with unfamiliar shows of dissent. Unfamiliarity in this case breeds contempt, and at the root of this contempt is an unwillingness to listen to disabled people, either as individuals or through their representative bodies (Brisenden 1989, p218). Self-advocacy, self-help, collective action and disability politics are incongruent with an individual model of disability (Oliver 1996). Instead, a more embracing perspective is needed to build a 'new world', which rejects historically oppressive discourses such as Social Darwinism (Zarb 1992,

Finkelstein and Stuart 1996). The next section introduces an alternative model of disability that appears to fit more readily with the self-empowerment of disabled people.

(2) 'The disabled self-advocate' - the social model of disability

'My day's going to come through ... I'm going to tell them the truth. They know the truth. All this petty nonsense' (Ed Murphy cited in Bogdan and Taylor 1982, p77).

Throwing back the stones

Re-defining disability as a political category has been at the heart of the disability civil rights movement (Schlaff 1993). According to Finkelstein and Stuart (1996), Campbell and Oliver (1996) and Shakespeare and Watson (1997), in the 1970s a number of disabled people started to articulate an emancipatory alternative to the individual model. This other way of viewing disability has been termed the **social model of disability** or social oppression model (Abberley 1987, Oliver and Zarb 1989, Oliver 1990). As the disability movement's 'big idea' (Hasler 1993), a key component of the social model is the distinction between impairment and disability. The Union of the Physically Impaired Against Segregation (UPIAS) was amongst the first to provide such a distinction in their 1976 'Fundamental Principles' document:

'Impairment - lacking part of or all of a limb, or having a defective limb organism or mechanism of the body'.

'Disability - the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities' (UPIAS, 1976 pp3-4, Quoted in Oliver 1990, p11).

These definitions, by contrast with dominant discourses that locate disability in the realms of individual impairment, direct the social model to uncover the ways in which society disables. Impairment and disability are not synonymous terms (Oliver 1990, BCODP 1992, Barnes 1993, Morris 1996). Instead disabled people are just that - people disabled by a contemporary social, economic, cultural and political climate on the basis of their purported impairments.

A number of studies exemplify the concerns of a social model. In 1981, Finkelstein illustrated the disablement of modern culture by describing an imaginary community where wheelchair users were the majority. In this disability culture, as opposed to disablist, able-bodied people were marked by bruises from banging their heads on lowered entrances and suffered backache from stooping down. They were helped by able-bodied equipment such as helmets, neck braces and, 'best of all', amputation! Money was collected for them in up-turned helmets with, 'Help the able-bodied', imprinted on them (Finkelstein 1981). Barnes (1990) examined the effects of day care settings on disabled people. He concluded that disabled children were not only assigned a position of dependency (the 'Cabbage syndrome'), but that when they challenged such a condition this contrasted sharply with the positions allotted to them in the professionalised climate. Jenny Corbett (1991) denounces notions of abnormality that are fundamentally located in

white, middle-class, male, able-bodied definitions of 'otherness' - step out of the 'disabled role' and you flout the rules. Barnes (1993) examined the media representations of disabled people. He found that in most cases two general images emerge. First, disabled people are 'super-cripples', overcoming their impairments at all odds (heroes in a tragic tale). Second, tragedy figures are well-represented (victims of impairment). In the latter case, impairment gets the better of human resources - distress, bitterness, anger or pathetic reactions being expressed. He observes that on television news-reports disabled people might get a mention, if they are lucky, for bravery (e.g. wheelchair race in the London Marathon) or for pity (e.g. fighting against impairment through new drug trials).

Defining the future

Literature of the social model not only examines the ways in which society excludes, discriminates and stigmatises people with impairments. It also suggests ways forward for emancipation that do not mean having to overcome one's impairment (see for example Corbett 1991, Oliver 1993). Instead, freedom comes with a change in society (Oliver 1990, 1996, Campbell and Oliver 1996). Protests by disabled people have appeared in the British Council of Disabled People (BCODP), the Direct Action Network (DAN), Independent Living Schemes, and, of course, the self-advocacy movement. As Campbell and Oliver (1996) document, these organisations *of* disabled people present a challenge to disabling society. The *Rights Not Charity* newsletter of the BCODP and journals such as *Disability and Society* continue to parallel in theory and writing many of the actions of political activists (Ibid., Johnston 1997). Hales' (1996) edited collection explores the care and support of disabled people in terms of a

social model where, for example, a new type of welfare system is presented reflecting a disability culture rather than a disabling culture (Finkelstein and Stuart 1996, see also Morris 1993b).

As the social model matures, calls for types of social change become more diverse (Finkelstein 1993, Oliver 1996)[4]. Campling (1981) along with Morris' (1991) 'Pride against Prejudice' and (1996) 'Encounters with Strangers', both link together politics and theory in ways that are sensitive to feminist issues. In the latter study, Morris writes about feeling excluded by both feminists and the male-dominated disability movement (see also Wendell 1996). Similarly Stuart's (1993) focus on 'double oppression', being black and disabled, argues for a 'race' sensitive social model, while Zarb and Oliver (1993) show how similar practices pathologise both ageing and disability. Even in view of this diversity, all proponents of the social model assert that to enable emancipation, society must no longer disable.

The social model and people with learning difficulties

The social model of disability is not reserved for people with physical impairments, although it may often seem that way (Ferguson 1987). As early as 1956 Dexter (see also Dexter 1958) argued:

'We need to see mental defectives in terms of the general theory of social problems' (Dexter 1956, pp10-11).

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[4] See Swain, Finkelstein, French and Oliver's (1993) *'Disabling Barriers - Enabling Environments'* which bring together many of these diverse strands within the social model.

Over the last thirty years a whole collection of literature has explored learning difficulties as a social creation of a disabling society. Examples include the following. Taking further Goffman's work (1961, 1963), Edgerton's (1967) ethnographic relationships with 'mentally handicapped' patients illustrated the stigmatisation of labelling and institutionalisation. Similarly, Morris' (1969) 'Put Away' and Braginsky and Braginsky's (1971) 'Hansels and Gretels' uncovered the experiences of adults and children with learning difficulties in institutions. Bayley's (1973) exploration of mental handicap in the community, noted the social limitations of support and debilitating effects on community memberships (as did Mercer's 'Labelling the Mentally Retarded' that came out that same year). O'Donnell's (1976) assessment of resident rights highlighted the concerns that even the most institutionalised demand. Brechin, Liddiard and Swain's (1981) 'Handicap in a Social World', and Brechin and Walmsley's (1989) 'Making Connections', piece together the experiences of people with physical impairments and learning difficulties (see also Kurtz 1981). While, the anthropological studies of Turner (1980), Groce (1992), Langness and Levine (1986), Koegel (1981, 1986), Whittemore, Langness and Koegel's (1986) and Langness and Turner (1986), examine the cultural formations of retardation.

Furthermore, just as people with physical impairments have written about disability from their own perspective, so the accounts of people with learning difficulties have clarified the socially constructed nature of disability. Examples include 'The World of Nigel Hunt' (Hunt 1967), Ed Murphy's story by Bogdan and Taylor (1976, see also 1982), 'Tongue Tied' by Joey Deacon (1974), Kaufman's (1988) account of mother and disabled daughter and Atkinson and Williams' (1990) anthology of prose, artwork

and poetry. In addition, Korbin (1986) presents the life course of 'Sarah - a Down's syndrome child' to show the impact of social factors on development, and Lea (1988) refutes pathologising clinical definitions via the poetry of people defined by such criteria. Potts and Fido (1991, see also Fido and Potts 1989) collected the oral histories of a number of long-term residents in an English mental hospital, and Oswin (1991) uncovered people with learning difficulties' experiences of bereavement. Cheston (1994) provides the accounts of 'special education leavers', while Angrosino (1994) talks of how he collected life stories 'On the bus with Vonny Lee' and Booth and Booth's (1994) 'Parenting under Pressure' explores the personal stories of parents with learning difficulties [5].

Similar to the controversies in the social model, the multiple identities of people with learning difficulties have been highlighted. Downer and Ferns (1993) have argued that black people with learning difficulties have double identities that need to be addressed. While a recent piece by Powerhouse (1996), a refuge for women with learning difficulties, takes diversity even further - disabled women with learning difficulties calling into question the dominant male, physically impaired focus of the social model (Morris 1996). Dingham's quizzical statement in 1968 pre-empted much of the literature presented above:

> 'What should concern us is the mystifying fact that so many social scientists ... do not regard mental retardation as a social and cultural phenomenon. I say mystifying, because nothing in the probabilistic

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[5] See Stanovich and Stanovich (1979) for bibliography of writings by people with learning difficulties.

world of social scientific reality is more certain than the assertion that mental retardation is a socio-cultural problem through and through' (p76).

Perhaps Dingham will be reassured by developments that have taken place since.

The social model and self-advocacy - differing with impairment

In view of the literature presented above, many researchers now recognise the social nature of learning difficulties. Take for example Bogdan and Taylor's (1982, p15) statement:

'Mental retardation is, in fact, a socio-political not a psychological construction. The myth, perpetuated by a society which refuses to recognise the true nature of its needed social reforms, has successfully camouflaged the politics of diagnosis and incarceration'.

However, differences can be observed in the literature, as revealed in the following assertion by Levine and Langness (1986, p191):

'If there is one firm conclusion to be made ... it is that *mild* mental retardation is as much or more a social and cultural phenomenon as it is a medical - genetic or cognitive - psychological one ... The definition of retardation, then, and some of the consequences of being thus labelled are concomitants of social life' (My italics).

This quote highlights two things. First, that learning difficulties, just like disability in general, can be understood as a social phenomenon - a creation of culture, politics and society (Morris 1969, Korbin 1986). To find the origins of learning difficulties, we are encouraged to turn attention away from a focus on prescribed incompetence, onto a society that excludes, discriminates and stigmatises people so-labelled (Mercer 1973). However a second point emerges. Levine and Langness (1986) exemplify a sociology of learning difficulties that focuses on the social construct of 'mild' learning difficulties. While Groce (1992, following Edgerton 1967, Scheiner and Abroms 1980) estimates that 75% to 85% of all 'retarded' individuals are considered 'mildly retarded', this still leaves the disabilities of a number of individuals unaccounted for by sociological analysis.

As Ferguson, Ferguson and Taylor (1992c) and Watson (1996) argue, it would appear that where 'impairment' is 'less' then it is easier to frame a sociological understanding of learning difficulties. This attention to, and perhaps preoccupation with, the notion of 'impairment' has wide implications for an understanding of disability as a social phenomenon (Shakespeare and Watson 1997) and appraisals of organisations of disabled people (Campbell and Oliver 1996). People with learning difficulties may be excluded from a socially-grounded understanding of disability on the basis of their purported impairments. As Simone Aspis of *London People First* candidly writes:

> 'People with learning difficulties face discrimination in the disability movement. People without learning difficulties use the medical model when dealing with us. *We are always asked to talk about advocacy and our impairments as though our barriers aren't*

disabling in the same way as disabled people without learning difficulties. We want concentration on our access needs in the mainstream disability movement' (Quoted in Campbell and Oliver 1996, p97, my italics).

Pat Worth, a Canadian self-advocate, expresses similar misgivings:

'People see our disability only, they don't see our ability. We may have a handicap but *we're* not the handicap' (Quoted in Yarmol 1987, p28, italics in original).

A preoccupation with impairment may ignore fundamental components of a social model of disability - self-help, collective and political action and self-advocacy (Oliver 1996). In addition, naturalised views of impairment take no account of learning difficulties' literature that has examined impairment as a social construction. The knock on effect of such ignorance is that disability becomes, in effect, a synonym for physical disability and people with learning difficulties are excluded (Ferguson 1987, p53). The next section draws together the social model of disability and literature that examines learning difficulties as a social and cultural artefact. Consequently, a theoretical basis is provided for an appraisal of self-advocacy in this thesis.

(3) 'The person with learning difficulties' - an 'inclusive' social model of disability

'Oppression is extreme. Their [people with learning difficulties] major handicap is the straight jacket of isolation imposed on them by

society. The result is a lack of life experience and self-confidence'
(Worrel 1988, p6).

Dealing with disability and impairment

Using the UPIAS's (1976) 'Fundamental Principles' distinction between
impairment and disability, on which the social model of disability was
formulated (according to Oliver 1990, 1996, BCODP 1992, Finkelstein and
Stuart 1996, Shakespeare and Watson 1997), people with learning difficulties
can be encompassed in the definition of *disability*:

> 'Disability - the disadvantage or restriction of activity caused by a
> contemporary social organisation which takes no account of people
> who have physical impairments *[or learning difficulties]* and thus
> excludes them from mainstream social activities'.

However, learning difficulties problematises the UPIAS's definition of
impairment. The social model represents impairment as opposite in
character to disability, the former not being seen as socially produced
(Hughes and Paterson 1997, p329). By contrast, the complexity of 'mental
impairment' has long been recognised in sociological literature on learning
difficulties (Watson 1996). As presented below, the social bases of
impairment, with respect to learning difficulties, have been demonstrated by
deconstructing dominant clinical criteria that are used in diagnosing an
'impairment of mind'. On reviewing diagnoses of mental retardation, Ryan
and Thomas (1980, later 1987) observed three diagnostic criteria: low
intelligence, social incompetence and maladaptive functioning. While these
criteria are assumed to originate within the individual (as indicative of

impairment), by contrast, the historical, political and socio-cultural bases of these criteria have been demonstrated (Levine and Langness 1986). Whereas the social model has, in effect, exiled impairment from sociological consideration (Hughes and Paterson 1997, p329), a whole body of literature has demonstrated the social nature of criteria used in diagnosing learning difficulties. Some of this literature is presented below.

Criterion 1 - The social creation of a 'lesser intelligence'

Korbin (1986 pp20-21) asserts that the discrepancy between chronological age and exhibited competence in people with learning difficulties questions rather than clarifies the individual origins of low intelligence (and hence impairment). Amongst many others, Townsend (in Morris 1969) criticises intelligence tests on the basis that they measure only a limited number of abilities, crudely approximate scores which can quickly increase following short-term educational intervention, and discriminate against certain class, cultural and ethnic groups. Moreover it would appear that the very presence of low intelligence is a direct product of disabling society:

> 'The educational system can be said to *produce* mentally handicapped people... Despite the fact that they develop slowly, their education - by contrast with that of many 'normal' children - stops short at sixteen. It is therefore hardly surprising that some handicapped people complain that they were never given adequate opportunity to learn to read and write' (Ryan and Thomas 1980, pp22, italics in the original).

Numerous studies have demonstrated the socio-political origins of lowered intelligence (e.g. Bayley 1973, Mercer 1973, Turner 1980, Whittemore,

Langness and Koegel 1986). One of these, Mercer's (1973) 'Labeling the Mentally Retarded', accessed what Townsend (1969, pxvii) termed the 'strong social element in the identification of handicap'. For Mercer (1973), a 'social system perspective' explains the origins of learning difficulties, and in doing so, deconstructs individualistic clinical criteria.

It is often assumed that a low score on an intelligence test is a symptom of impairment. There is a tendency to assume that 'minimal brain dysfunction' exists, even when it cannot be detected, 'because of the inadequacy of present diagnostic tools' (Mercer 1973, p8). However, Mercer outlines a number of stages in children's schooling that lead to the diagnosis of low intelligence and hence 'mental retardation'. The origins of learning difficulties can be found not in 'minimal brain dysfunction', but in the employment of IQ testing and discriminatory referral processes by teachers and professionals. Tomorrow's playground insults are foretold by today's professional diagnoses (Ferguson 1987, p51).

For Mercer, the process of 'labelling the retarded' starts with the administering of IQ tests. Stage 1, 'Enrolment in public school', recognises immediate class and race biases in the discovery of 'the retardate' (sic). No students in the private school Mercer appraised were subjected to IQ testing and were not, therefore, drawn into the diagnostic trap. However, for public school students entering Stage 2, 'Normal student in the regular classroom', the labelling process continued and where 'primarily the expectations of the teacher determines who will be identified and referred as a possible candidate for the status of retardate' (p103). Assessment procedures were tied up in an ethos that reinforced the norms of the school, rewarding intellect and punishing failure. All but two of the 71 students placed in special education

classes were recommended by their teacher. This critical period in the classification of otherness (52 of the 71 were defined mentally retarded before the 5th grade) was dependent upon teachers' subjective criteria justified by reference to 'valid', 'reliable' and 'scientific' intelligence testing procedures. By Stage 3, 'The retained student status' those labelled were retained for a grade or more. Already non-Anglo students were well represented in this remedial population. Stage 4, 'Referral by the principal' for psychological assessment occurred if the student, caught up in a vicious cycle of failure and punishment, continued to under-achieve. For many this led to Stage 5, 'Psychological testing and evaluation', where the IQ test re-appeared:

> 'Once tested a child's IQ becomes the most critical variable determining whether he retains the status of normal student or moves closer to the status of the retardate' (p114).

However, the key to a diagnosis of low IQ (and therefore handicap) appeared to lie in the referral process. Those pupils referred by a teacher or principal were most likely to be tested (76%), the remainder who were not referred by professional authority 'escaped the risk of being assigned the status of mental retardate'(p113). Moreover, reasoning behind referrals highlights further the social bases of diagnosis. Most children were referred, tested and hence labelled, when they were perceived as having 'academic difficulties' (7 out of 10 tested). Only 4 out of 10 testees were referred because of 'behavioural difficulties'. Academic success, so highly valued in society, impinges directly on diagnosis. In this stage,

> 'As soon as the intelligence test was used, the higher failure rate of children from lower socio-economic backgrounds and from minority

homes produced the disproportions characteristic of classes for the mentally retarded' (p115).

This discrimination continued in Stage 6 'The labeling' and Stage 7 'The labeled' where non-Anglo, working class children were statistically more likely to be placed in special schools even when their IQs were not significantly lower than those not recommended for placement. In Stage 8 'Vacating the status of retardate', a final chance for graduating from the status of 'retardate' was permitted. Those that did graduate were those deemed to have a 'high' IQ and a low probability of neurological deficits (i.e. they were 'physically educable'). Mercer concludes:

'On the basis of our social system epidemiology of mental retardation in the community, that institutionalised Anglo-centrism is a recurring pattern in the labeling process, a pattern that is closely linked with the statistical definitions of 'normal' and the IQ test' (p123).

Identifying the sociological and cultural bases of inability appears to be important:

'Any conceptualisation of 'intelligence' that does not allow for these factors (and for racial attributions, culture and gender) is fatuous; conversely, one that does make allowances would be so weak as to have relatively little content' (Borthwick 1996, p408).

Miles (1992), in considering the socio-cultural construction of mental retardation in Pakistan, notes how the nation's high rate of non-literacy creates a very different population of 'retarded'. In a climate of Social

Darwinism, the development in late 19th century Britain of a national school system, brought to light those who could not be accommodated in that system (Townsend 1969, pxxii). So occurred an expansion in the proportion of those in society who were identified as 'mentally handicapped'. In today's system, people with learning difficulties continue to be disabled of skills and hence intelligence throughout childhood (Korbin 1986). People are forced to adapt to inadequate practices and disabling educational systems (Apple 1982, Bratlinger 1985, Oliver 1996). Skrtic (1995c p212) notes that even when the needs of a disabled client do not match the professional's repertoire of skills, there is still a tendency to force the client artificially into available standard practices - de-skilling them thus. Low intelligence, a facet of learning difficulties, appears to have social origins.

Criterion 2 - The creation of 'social incompetence'

Guskin (1963) observes that people with learning difficulties are expected to play a generalising and all-encompassing role. Acting like a retarded person can soon become second nature (Kurtz 1981, pp14). As Barnes (1990) points out, social incompetence within a social order that emphasises the dependency of disabled people, may be no more than a reflection of the paternalistic role of the state:

> 'The level of incapacity accepted for special attention and care depends on the perceptions and tolerance of families, peer groups, *the community and bureaucracy*' (Townsend 1969, pxx, My italics).

In deconstructing the notion of social incompetence, literature tends to focus upon ideological, structural and bureaucratic practices. For example, Koegel

(1986) pinpoints a number of prevalent assumptions that shape the socialisation of people with learning difficulties, potentially augmenting their incompetence. These include, that they remain children (never reach adulthood), are the same (homogeneous group), that their impairments affect all their actions (the reductionist cause and effect reasoning for Mercer 1973) and that 'they' are more different than 'us'. Yet, for Morris (1969), people are labelled and defined not because they are of subnormal intelligence or are incapacitated but because they are deemed incomplete and deviant. Ryan and Thomas (1980, pp26) point to societal structures that phrase people in terms of their lacking capacities. There is a tendency to attribute behaviour to individual inability, whilst failing to examine the deficiencies within the person's environment (Oswin 1991).

> 'Implicit in these statements is the assumption that the condition characterises the individual and that the condition exists as an entity regardless of whether the person is aware of its presence or aware of others recognizing his pathology' (Mercer 1973, p7).

Such assumptions have implications. For example a zoo on the Isle of Wight refused entry to a group of people with learning difficulties (*The Guardian, 6 July 1996, p4*) The manager argued:

> 'It was in the best interests of the zoo and the poor people in the group ... the adults were severely disabled and I was very concerned they may harm the animals. One even had a fit ... and was trying to bite. Nobody but an idiot would have let them in'.

Taken further, Gunn (1990) outlines a number of legal deficiencies which position people with learning difficulties as incompetent. These include ineligibility for jury service, imposition of limits on sexual relationships (see Kennedy 1996), lack of adequate sex education (Brown 1994) and exemption from paying community charge. Social incompetence is the legal requirement of people with learning difficulties (Hudson 1988).

As basic rights are withheld so the possibilities for taking on socially competent roles perceived are limited. Ferguson found in 1987 that 50 to 80 percent of disabled people are unemployed. In 1989, although estimates were conservative (Barnes 1991), Martin, White and Meltzer found that only 34% of disabled people under pension age living at home were working. The 1995 Disability Discrimination Act (HMSO 1995) does not appear to improve matters.

The act legitimates forms of exclusion that will continue to decrease the life chances of disabled people (see Barnes 1996b). This is apparent in the Act's position on employment (Part II) where employers may justify discrimination. An employer can reject a disabled job applicant if an individualised assessment of the 'risk', carried out by an expert, taking into account the feasibility of 'reasonable adjustments' (that is adjusting the work environment to accommodate another's impairment) designates that applicant 'unemployable' (Gooding 1995, p18). Barnes (1996b) argues that this focus upon individualised assessments reinforces the power imbalance between disabled applicant and expert assessor, with disabled people having to prove themselves worthy of consideration for employment. The job interview starts sooner for disabled applicants than for non-disabled applicants. Furthermore, significant sections of the workforce are excluded from the provisions of the

Act. These include small businesses (fewer than 20 employees). The detrimental effects upon people with learning difficulties are potentially massive in light of the many small workshops and businesses that employ people so-labelled. The Department of Trade and Industry (HMSO 1996) brought out a pamphlet on small businesses with the headline cover, '96% of all firms employ fewer than 20 people'. Social incompetence appears to be prescribed constitutionally, and organisational forms reinforce 'handicapped behaviour' (Townsend 1969, pxxi).

Criterion 3 - The creation of 'maladaptive functioning'

Hot-topics for practitioners, particularly in psychology, are the 'challenging' or 'maladaptive behaviours' of people with learning difficulties[6], which can be defined as:

> 'Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson 1995, pp4-5).

Ideologically such behaviours are seen as reflecting some underlying 'impairment'. Assumptions find their way into expert opinion For example, Kennedy (1996, p123) reports of a paediatrician who on examining a child with 'hypnotonic spastic quadriplegia' (sic) found vaginal injuries, anal scars

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[6] See, for example, the many workshops, conferences and training programmes advertised in the *Bulletin of the British Psychological Society*, for an illustration of how fashionable challenging behaviour is amongst practitioners.

and a sexually transmitted disease. He reported, 'These symptoms could be due to an obscure syndrome'. In addition, Goodwin (1982) recalls the case of a paediatrician belatedly and reluctantly reporting three boys who were having sexual intercourse with their retarded sister. His 'excuse' was 'Isn't it better to save three normal boys than one retarded girl?' Similarly, Kennedy (1996, p123) reports the case of a counsellor's comments to a mother whose disabled son had been sexually abused - 'At least it didn't happen to one of your non-disabled children'.

Brechin and Walmsley (1989, p7) observe that because some professionals view 'problem behaviour' as normal for people with learning difficulties, the symptoms of child sex abuse are understood as the inevitable consequence of handicap. By contrast, in-keeping with a sociology of learning difficulties, a number of observers have suggested that the origins of maladaptive or challenging behaviours can be found in cultural, social and political structures. Shearer (1981a) suggests that maladaptive behaviours reflect outwardly the management of 'spoilt identities' (Goffman 1963) - the impact of other social actors' responses:

> 'At any given time for any given individual it may not be possible to differentiate between behaviour that is a consequence of the retardation and behaviour that is a consequence of behaving as one thinks the expectations of others define proper behaviour' (Kurtz 1981, p14).

According to Ferguson, Ferguson and Taylor (1992a) in 1973 the entire category of 'Borderline Retardation' was dropped from the Manual of Terminology of the American Association on Mental Deficiency. What

constitutes 'maladaptive behaviour' varies from decade to decade. Indeed, for Emerson (1995, p5), many challenging behaviours may actually be functionally adaptive responses to exclusive environments. Often the most apparently irrational maladaptive behaviours are themselves forms of resistance. Genealogically, perceptions of (ab)normality become mis-shaped over the years. For example the term 'idiot' comes from the Greek word 'idiote' meaning 'private person'. Privacy was devalued in Ancient Greece. Later the term was applied to those very people who were deemed in need of privacy and segregation from wider community, but ancient values remain attached (see Parker, Georgaca, Harper, McLaughlin and Stowell-Smith, 1995, p16).

Oswin (1991) explored the bereavement experiences of people with learning difficulties. She found that often people were not told that a family member had died for fear that, 'They were not up to such news'. Some of Oswin's informants were not told until some years afterwards. Even when the loss of a family member was disclosed, any outward display of grief by people with learning difficulties' tended to be noted down by care assistants and psychologists as 'challenging behaviour':

> 'Any alterations in behaviour following loss are usually attributed to the original diagnosis that person has already' (French and Kuczaj 1992, p108).

However, anger may be a functionally adaptive response to bereavement (heightened when the effects of institutionalisation are taken into account). Nevertheless, people with learning difficulties are viewed solely in terms of their purported 'impairments'. Not only are 'patients' pathologised by the

diagnostic classification itself, they are further pathologised when they do not fit criteria (Parker, Georgaca, Harper, McLaughlin and Stowell-Smith, 1995, p3). A response of crying on hearing the death of a loved one may be seen as overly-emotional, passive and dependent, indicative of 'retardation'. By contrast, lashing out in anger is likely to be viewed as challenging behaviour. A double-bind exists, whatever the response, a diagnosis looms.

'If someone else whispers a lot during the play people might ignore it or get angry. If we whisper it is because we are retarded. It's like we have to be more normal than normal people' (Martin Levine, self-advocate, in Freidman-Lambert 1987, p15).

Zetlin and Turner (1985, p575) examined the case reports of professionals. In them were many incidents of 'problem behaviour', including minor violations such as the regular use of marijuana and associated 'uppers', 'and / or the daily consumption of a sizeable quantity of beer by two sample members'! Here a professional's own sense of right and wrong becomes implicated in assessing the suitability of behaviour.

Consequently, assessment techniques for challenging behaviour are low in validity and reliability, simplistic and inappropriate (Emerson 1995, p177). Assessment also ignores the cultural and social processes that help to shape others' reactions to challenging behaviour. Rusch, Hall and Griffin (1986) found that those institutionalised people with learning difficulties defined as having challenging behaviour were most likely to be abused by staff and other inmates (indeed a diagnosis of challenging behaviour was the major predictor of subsequent abuse). Moreover, 1 in 40 of ward staff in Canadian hospitals said that their typical response to a patient exhibiting self-injurious

behaviour was to hit them. As with Mercer's (1973) cycle of denied educational opportunities and consequent lowering of intelligence, challenging behaviours once culturally-defined may be re-constituted and reinforced through a process of abuse.

Finally, medical abuse has been identified in considering the origins of maladaptive behaviour. Up to 40% of community residents and 50% of institutionalised people with learning difficulties receive psychotropic medication for 'challenging behaviours' (Emerson 1995, p15). In 1987 the Ohio Legal Rights Service survey reported that up to 70% of people with learning difficulties were using neuroleptics. In America alone, over one million children are prescribed drugs to control their behaviour in schools and at home (Breggin 1993). Common drugs include Ritalin, neuroleptics and antidepressants. There are consequences. Anti-psychotic medication affects muscle tension, sedates or 'snows' thought and gives rise to tardive dyskinesia (involuntary shakes) and decreases the rate of learning (Kuehnel and Slama 1987). Similarly, some evidence suggests that Ritalin causes brain damage (Breggin 1993).

Surprisingly, even when people with learning difficulties are subjected to a multitude of maladaptive environments, only a small proportion of them exhibit challenging behaviour (Humphreys, Evans and Todd 1987, p9). For Clegg (1993, p390), professional practice must take into account:

'Important psychological issues such as coping with chronic lack of self-esteem or *surviving within damaging social environments*' (My italics).

After all, people subjected to such environments are aware of the impacts, as Ed Murphy notes about his girlfriend:

> 'I don't think that retardation is holding her back so much as emotional problems. If she had confidence that would make the difference. I know she could build herself up' (cited in Bogdan and Taylor 1982, p74).

Too often there is a tendency to view people with learning difficulties in terms of their 'deficits' (Ryan and Thomas 1980, p82, Booth and Booth 1994). When allowed into the community perfection is demanded. Any deviation from the perfect path to community membership and 'they' may be recalled, incidents of maladaptive actions being cited. However, attending to what people are able to do, even when society attempts to banish them from mainstream life, recognises their 'capacities' and the tendency for all of us to attach significance to the 'truth' of individual impairment. Maladaptive behaviour may be testimony to the historical exclusion of people deemed inhuman.

A social model of impairment

The social model of disability does not deny that some illnesses may have disabling consequences (Oliver 1996 pp35-36). However, the UPIAS's definition of impairment appears to be inappropriate in light of the literature cited above that has deconstructed the criteria used in diagnosing 'impairment' in people with learning difficulties. Koegel (1986, p47) warns:

'However much we pay lip service to the influence of socio-cultural factors, we *do* primarily see mental retardation as a biomedical phenomenon and *do*, as a result, tend to attribute incompetent behaviour exclusively to physiological causes' (Italics in the original).

While people with learning difficulties may have some difficulties learning, it is difficult to separate their organic and social origins (Sleeter 1995, p162). Therefore:

'The most relevant issue here is not what causes mental retardation - or blindness, or any other physical disability - but why some cultures regard it as seriously troublesome and others do not. About this subject, we remain almost wholly ignorant' (Edgerton, 1976, pp62-63 quoted in Oliver 1990 pp15-16):

In a review of 307 research studies in learning difficulties, Kavale and Nye (1981) found little consensus regarding its individual and physical origins. A way forward is the adoption of a social model that de-biologizes and de-medicalizes both disability and impairment (Hughes and Paterson, 1997, pp330-331). Shakespeare and Watson (1997) assert that a social model of disability (and to that add learning difficulties) provides a model to understand disability and impairment, thus working towards a 'non-disablist culture' (see Finkelstein and Stuart 1996).

For this thesis, bringing together literature from the social model and the sociology of learning difficulties fields appears to provide a platform on which to understand self-advocacy in the lives of people with learning

difficulties. The social model reminds us that society has to change and this change will come about as part of a process of political empowerment of disabled people as a group (Oliver 1996, p37). Self-advocacy and an inclusive social model appear to be compatible.

Conclusion - an 'inclusive' social model of disability and an appraisal of self-advocacy

'First, we need a sociology of those who study mental deficiency ... second, we badly need a sociology of those who work in institutions ... third, we need to see mental defectives in terms of the general theory of social problems' (Dexter 1956, pp10-11).

This chapter has introduced two models of disability and reviewed relevant literature. The first, the individual model exists in dominant practices and appears to subjugate people with learning difficulties. By contrast, the social model of disability provides a context in which self-empowerment is located. In addition, with respect to the self-advocacy of people with learning difficulties, it has been argued that a social model of disability benefits from an incorporation of literature associated with a sociology of learning difficulties. This literature tackles the social construction of 'learning difficulties' while recognising the resilience of people so-labelled in disabling environments.

Combining the social model with a sociology of learning difficulties may be termed an 'inclusive' social model of disability. This model embraces the ambitions of disabled people whilst being sensitive to the impact of disabling society. This thesis will draw upon an inclusive model to appraise self-

advocacy in the lives of people with learning difficulties. As Campbell and Oliver (1996, p169) point out, the disability movement has:

'Succeeded in giving a voice to disabled people ... the crucial issue for the movement over the next few years is to make sure this collective voice is not merely heard but taken notice of'.

The voices of self-advocates will be central to an appraisal of self-advocacy in this thesis. This appraisal can in some small way build upon a social model of disability through the inclusion of the perspectives of people with learning difficulties who are involved in their own self-determination. This leads on to questions of methodology, method and analysis that are considered in the next chapter.

Chapter 4

Exploring self-advocacy: Research questions, methods and analysis

Introduction

The previous two chapters have introduced the self-advocacy literature and presented an inclusive social model of disability as a theoretical ally to the self-determination of people with learning difficulties. From this point onwards this thesis aims to answer three questions. First, what is the nature of the contemporary self-advocacy movement? Second, how do self-advocacy groups impact upon the lives of people with learning difficulties? Third, how do self-advocacy groups work? Various methodologies, methods and analyses are employed in this thesis to answer these questions. A postal survey of self-advocacy groups, the life stories of five self-advocates and an ethnographic study of four self-advocacy groups, form the empirical basis of this thesis. In this Chapter each are introduced and critically evaluated.

Section 2 - Examining the contemporary self-advocacy movement

The first of the empirical sections of this thesis, section 2, examines the contemporary state of the self-advocacy movement. Reference will be made to the findings from a postal survey of self-advocacy groups.

The postal survey

The postal survey was carried out to gain an overview of the British self-advocacy movement and to find the whereabouts of a small number of groups that would be later contacted for follow up study. There has only been one national survey of self-advocacy groups (Crawley 1988). Crawley's study highlighted a number of tensions within self-advocacy but concentrated on groups in adult training centres (ATCs) and hospitals. It remains to be seen how self-advocacy has been taken up in the community (Crawley 1990, Mitchell 1997). The aim at the outset of the postal survey was to contact every self-advocacy group in a variety of contexts in the UK.

The survey pack

Previous attempts to access the views of people with learning difficulties have highlighted the benefits of accessible methods[1]. *People First London* advise researchers to use straight-forward language and support prose with

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[1]See for examples O'Donnel 1976, Howie, Cuming and Raynes 1984, Taylor and Bogdan 1984, pp114-118, Flynn 1986, Flynn and Saleem 1986, Lowe and de Paiva 1988, Lea 1988, March 1992, Barnes and Wistow 1992, Minkes, Robinson and Weston 1994, Dagnan, Dennis and Wood 1994, Mackensie and Langa 1994, Longley and Collins 1994, Bashford, Townsley, and Williams 1995, Walmsley 1995.

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pictures[2]. Crawley's (1988) questionnaire lacked an accessible format, resulting in an over-representation of advisor respondents, something she later regretted. Accordingly, the questionnaire used in this thesis was written with self-advocates in mind. Many of Crawley's items were used and accompanied by an appropriate drawing (see *Appendix section 2, 4*). Nine questions were posed, with extra space being given for further comments, group addresses and identity of the respondent (i.e. advisor, self-advocate(s) or both). Characteristics examined included; (1) name of group, (2) number of members and who they were (i.e. self-advocates, members of staff, parents, advisors), (3) time and (4) place of meetings, (5) age of group, (6) presence (or absence) of advisor and their status (staff, parent or other and whether paid or voluntary), (7) roles within group (i.e. chairperson, secretary, treasurer), structure of group meetings (e.g. evidence of minutes, agenda and election procedures), (8) description of group discussions and (9) sources of funding (local / health authority, charitable, self-funded and others). The survey pack contained:

- A covering letter (*Appendix 2, 2*) in two formats. Letter 1 was addressed to self-advocacy groups; letter 2 to individuals (carers, professionals, individual self-advocates) and organisations (centres, voluntary organisations, etc.).

- An introductory booklet (*Appendix 2, 3*) illustrated to explain reasons for carrying out the survey and to present the wider research project.

- A questionnaire (*Appendix 2, 4*)

- Stamped addressed envelope by which to return responses.

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[2] See for guidelines *'Making it easy first'* project and for examples, *Outside But Not Inside...Yet.* , *Your Right to Housing and Support*, *Safer Sex Pack*, *Oi! it's My Assessment*, *Laws About Our Rights - Civil Rights (Disabled Persons) Bill.*

Respondents

A comprehensive list of groups in Britain was required. Therefore a number of self-advocacy groups were contacted. All contacts said that no list existed because it was impossible to keep track of the movement's developments, what with so many groups starting up, or folding, month after month. Although not ideal, a sample of 364 respondents was obtained from a high-profile *People First* group[3], allowing the postal survey to go ahead. Respondents included supporters, individual self-advocates, parents, carers, professionals and various voluntary organisations, centres, schools, hostels, group homes and hospitals, as well as self-advocacy groups. In total, 330 'survey packs' were sent out between August and December of 1995.

A pilot study of the first 30 respondents was carried out in late September 1995. In the first batch of returned questionnaires a number of respondents asked for more information. Consequently, the introductory booklet (*Appendix 2, 3*) was included in all later mailings. Respondents in the pilot group were sent the booklet later. In addition, space was added to subsequent questionnaires to identify the respondents. Of the 330 packs sent out, 40 % were returned by self-advocacy groups. 23 were sent back uncompleted ('Group not know at this address'), or filled in by individuals who were not members of self-advocacy groups. Most respondents were based in England.

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[3] Respondents were recipients of the group' newsletter, which has a national readership (see *Appendix 2, 1* for correspondence).

Analysis of survey findings

Findings obtained from 134 respondents were quantitatively analysed on SPSS by September 1996 (see *Appendix 2, 5* for coding schedule). Analysis was threefold. First, a descriptive overview of the characteristics accessed by the questionnaire items was carried out. Second, group discussion topics were thematically analysed (item 8). These themes were labelled and surveys coded to see whether or not each theme was explicitly mentioned (see the last page of *Appendix 2, 5* - 'Coding of discussion themes'). Third, the data set of 134 groups was analysed to assess the incidence of various group types, as described in the 'group typology' literature presented in Chapter 2. These analyses are presented in Chapter 5.

Methodological limitations

Findings from the postal survey only scratch the surface of the self-advocacy movement - providing a wide but shallow description of self-advocacy groups. Following Allport (1947, pp56-57), Harré (1981, p9) and Bryman (1988, p52), focusing on the structural surface of social phenomena (self-advocacy groups) does not extract the meanings of those phenomena in the lives of relevant people (self-advocates). The questionnaire only touches upon self-advocates' accounts of self-advocacy, and then, only when respondents give 'further comments'. Furthermore, while attempts were made to make the questionnaire 'self-advocate-friendly', it remains unclear who really fills out the questionnaires (self-advocates or advisors). A participant of a study by Edgerton (1984b) stated, 'You gotta try to see things from my side too. I know people are trying to do good, but they don't know what it's like to be me'.

In keeping with the commitment of proponents of the social model of disability, the views of people with learning difficulties were sought in an appraisal of self-advocacy[4]. Section 3 of the thesis examines self-advocacy with reference to the experiences of self-advocates.

Section 3 - The impact of self-advocacy upon the lives of people with learning difficulties

The second empirical section of the thesis, section 3, examines the impact of self-advocacy groups on the life experiences of people with learning difficulties. These accounts come from insiders or 'emics' of the movement (Whittemore, Langness and Koegel 1986, p1) - self-advocates with learning difficulties. The following section considers the form of these accounts.

Life as narrative

Bowker (1993) suggests that an age of biography is upon us. Accordingly, a current frame of reference in the social sciences is the epistemological notion that meaning and experience are constrained in texts (Potter and Wetherell 1987, Burman and Parker 1993). Various approaches study texts to throw light on personal and social life[5]. One of these approaches is narrative inquiry (Clandinin and Connely 1994).

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[4] According to Sutcliffe (1990, p21) and Campbell and Oliver (1996, p1), organisations of disabled people are best understood from the inside.

[5] Approaches sensitive to text include interpretivism (e.g. Ferguson 1987, Ferguson, Ferguson and Taylor 1992a, b and c), post-structuralism (Burman and Parker 1993), social constructionism (Berger and Luckmann 1987, Potter and Wetherell 1987, Gergen and Gergen 1988, Sarbin 1986), ethnomethodology (Garfinkel 1967, 1968), ethogenics (Marsh, Rosser and Harré 1978), grounded theory (Glaser and Strauss 1967, Schatzman and Strauss 1973) and critical discourse analysis (Fairclough 1989,1992, Parker 1997).

Narrative inquiry is concerned with the storied nature of life (Bruner 1986, 1987). When a person notes something about their experience they often do so in a storied form (Clandinin and Connely 1994, p414). Some proponents of narrative inquiry would assert that stories are *the* central component of experience and reality (Didion 1979, Hoffman 1993, Sarbin 1986, Bruner 1987, Gergen and Gergen 1988, Gergen 1988, 1994). Narrative is seen as producing experience, and vice versa. People impose structure and give meaning to their lives through the use of stories (Hoffman 1993). People tell stories in order to live (Didion 1979, p11), both in the telling and doing of self (Gergen and Gergen 1988). Some would suggest that because human beings are storytellers (homo narrans) and life is story put into practice (Gillman, Swain, Heyman 1997, p680), so people are texts (Gergen 1988). Alternatively, other proponents use narrative as a medium through which to present and reflect upon some of the experiences and realities of people (Allport 1947, Parker 1963, 1990, 1994, Plummer 1983, 1995, Langness and Levine 1986, Fairclough 1989, 1992). Here, reality and narrative are not necessarily seen as synonymous. Instead, because telling stories is a large part of what people do, storytelling is used as a method to lend some insight into the experiences and realities of narrators.

Narrative inquiry deals with the collection, writing up and presentation of stories (Plummer 1983). Accounts of people with learning difficulties have taken a number of narrative forms including: autobiography (Hunt 1967), biography (Deacon 1974), life story (Bogdan and Taylor 1976), oral history (Angrosino 1994) and life history (Langness and Levine 1986). This thesis draws upon the life stories of five self-advocates.

Life stories of self-advocacy

Life stories are life experiences presented in a storied form (Plummer 1983). A life story is the product of the reminiscences of one narrator that are structured together chronologically or thematically in a storied fashion (Bertaux 1981a). The life story relies on the accounts of a primary narrator whereas a life history combines different persons' stories of an individual (Plummer 1983, 1995). Life stories can be written alone or told to others who collaborate in writing (Goodson 1992, Sparkes 1994, Hatch and Wisnieswski 1995b). The aim in this thesis was to write life stories collaboratively with narrators (self-advocates). A recent paper has critically examined the use of narrative methods with people with learning difficulties (Goodley 1996a). Drawing on this paper, it would appear that the life story is suited to examining the impact of self-advocacy groups on the life experiences of people with learning difficulties. However, limitations exist alongside the strengths.

Strengths of the life story method

An invitation to personal stories

In an intensive literature review of narrative research in the learning difficulties field, Whittemore, Langness and Koegel (1986), revealed a tradition rich in the beliefs, perceptions and attitudes of parents, carers and professionals. The perspectives of people with learning difficulties were often not represented. According to Turner (1980), the absent accounts of people with learning difficulties reflects a general assumption that people so-labelled are unable to articulate their own life experiences. By contrast, presenting the life stories of disabled people implies that lives exist to be

recounted and addresses the absence of these lives in previous documents (Thomas 1982, Korbin 1986, p19, Thompson 1988, p2, Atkinson, Jackson and Walmsley 1997).

Addressing the abstract

Using life stories addresses the 'disappearing individual' in abstract social theory (Thomas and Znaniecki 1918-1920, Nicholson 1928, Whittemore, Langness and Koegel 1986). Stories allow personal insights into social worlds (Taylor and Bogdan 1984, pp7-8, Smith 1987), and theories of the social world, both lay and academic, can be assessed from an individual standpoint (Langness and Koegel 1986). As Schutz (1964) observed, theories flounder when they fail to adequately immerse themselves in the worlds of those they attempt to understand. Stories present subjective accounts of situations but also highlight social backgrounds (Corradi 1992, p106). Bertaux-Wiame (1981, p260) suggests that stories allow readers to listen beyond the words of narrators and to tap into the speech of their social culture. Abstractions can be checked by stories (Bertaux 1981b). Individual stories oppose over-deterministic understandings of the social world (Allport 1947).

Story and meaning

Life stories investigate some of the meanings held by narrators, and also, by readers (Bogdan and Taylor 1976, Thompson 1988 pp7-8, Smith 1987). Stories exhibit some of the meanings that narrators attach to experiences. In addition, readers' own meanings are called upon in reflecting on another's account. A knock effect may be that readers' preconceptions are re-evaluated in light of another's account (Koegel 1981, 1986), for example,

falsifying the assumption that the views of people with learning difficulties do not exist (Atkinson and Williams 1990, p8). Bogdan and Taylor (1982, p16) grandly claim that life stories enable us to understand society better, specifically to understand the meaning of 'mental retardation'. On a more modest level, life stories appear to fit the aim in this thesis of examining some of the meanings self-advocates' attach to 'self-advocacy' and self-advocacy groups.

Exploring the research process

Writing stories is a reflexive venture. Consequently, the writing process, as a research exercise, can be reflecting on and investigated (Nisbet 1976, Plummer 1983). Some writers, like Parker (1963), assert that the very exercise of writing someone else's story can expose the non-scientific and arbitrary nature of research. For others, using life stories fits in with a critical approach to research (Allport 1947, p127). Reflexivity in the social sciences is nothing new (Kidder and Fine 1997). In the 1930s, the Chicago school tradition in sociology encouraged researchers to provide a 'vivid sense of the research experience' (Warner and Lunt 1941, pp5-6, Stott 1973). Reflexivity can be used to assess the authenticity of research methods that purport to give voices to people (Lather 1991, Oliver 1996). Later in Chapter 8 some of the processes involved in the writing of others' stories are considered.

The limitations of the life story method

Only part of the story

Biographies are in a constant state of becoming (Turner 1991, pp232-233).

Today's story of a specific experience will read differently if told tomorrow. Life stories are made up of a narrator's reflections of some experiences from the past viewed at a specific time in the present. No single story can capture the range or richness of people's experiences (Bruner 1986, p143). Furthermore, when life stories are the product of collaborative, diachronic relationships (Whittemore, Langness and Levine 1986), as they aimed to be in this thesis, there is a danger that researchers surpress the disclosure of certain stories in favour of those that are of 'research interest'. Furthermore, moving from lives to text is problematic. As soon as speech is translated into prose, a story is mutilated (Thompson 1988, p230) and contaminated (Plummer 1983, p113). These effects become even more acute in collaborative life story research where the researcher primarily becomes the writer of another's oral account.

Bias in narrative

Harrison and Stina-Lyon (1993) argue that the credibility of a person's narrative is the extent to which the narrative remains faithful to the reality of the narrator. However, all narrators make errors. They may ascribe intentions to actions after the event, exaggerate, rehearse stories or lie (Oakley 1981, Bruner 1987, Rosie 1993, Plummer 1995). Suggestions to overturn these sources of error include, cross-checking information with other people, assessing how a person's narrative stands up against official documents and re-visiting stories with narrators (Klockars 1977, Taylor and Bogdan 1984). However, it may not be appropriate to ask if participants are telling the truth (Dean and Foot-Whyte 1978, Walmsley 1993). Why people present themselves like they do may be more important. Behind the presentation of stories are intentions (Moffet and McElheny 1966, Widdicombe 1993). Stories are told like they are for a variety of reasons that we may never know

about (Potter and Wetherell 1987). In this thesis, no attempt is made to excavate the intentions of narrators. Therefore, life stories are constructed from the reflections of narrators and are bound together by bias. Later, as the process of writing proceeds, so another source of bias enters the fray - researcher bias (see Chapter 8).

Problems with relying on stories

A preoccupation with stories may ignore the cut and thrust of contemporary political narrative and the unseen pressures of economic and structural change (Tomlinson 1995). Whyte's (1943) *Street Corner Society* was criticised by Stott (1973) on the basis that Whyte had become totally accepting of his narrators the 'Cornerboys'. He remained, therefore, uncritical of their contempt for college students, non-Italian teachers and social workers. Empathy with others' stories can prove to be a weakness as well as a strength. Moreover, debates rage over whether or not stories are good enough to 'stand alone' as markers of the phenomena under investigation (see Bogdan and Taylor 1976, p51). For Sparkes (1994) and Kidder and Fine (1997), life stories cannot stand-alone and require additional analysis. If this is the case, stories presented alone may lack a theoretical punch (Allport 1947). These debates about analysing stories will be returned to later in this chapter.

Problems with relying on story-tellers

It is helpful to the narrative researcher if narrators are articulate (Plummer 1983, p90). A consequence of this preoccupation with articulate people, has been the exclusion of those that cannot tell or have difficulties telling stories (Stott 1973, p195). Even when inarticulate people are included, researchers

and others may take on dominant roles in the writing exercise. While a number of imaginative strategies have been used to aid communication of people who lack articulation[6], questions remain about whose voice is dominant in the life story. Furthermore, if the narrative researcher fails to acquire the 'necessary' skills and creative heart of the novelist, poet and artist (Nisbet 1976, Plummer 1983), writing stories is further problematised. A weakness of the life story method is that the narrative's plot and fable may be lacking from the off (Chatman 1993) - the product of narrator, writer or both.

The life story method and talking to 'top self-advocates'

The life story method is not perfect. However, it is adopted in this thesis to examine the impact of self-advocacy on the lives of self-advocates. Chapters 6 and 7 respectively present and examine the life stories of five 'top self-advocates'. Furthermore, Chapter 8 of this thesis takes up the challenge of critically examining the life story as a method for imparting the experiences of people with learning difficulties. This, in some small way, fits the bigger project of developing emancipatory disability research (Abberley 1992, Oliver 1992).

The informants - 'top self-advocates'

> 'No one person's life can be wholly representative of an entire group, for each individual is unique. Yet I feel that a detailed examination of one life may provide insight into the larger question of how mentally retarded individuals are perceived in societies' (Groce 1992, p175).

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[6] See footnote 1 earlier

Chapter 6 presents the life stories of Jackie Downer, Lloyd Page, Joyce Kershaw, Anya Souza and 'Phillip Collymore' (a pseudonym). These five were chosen because of their extensive experience of self-advocacy. They are well known in the movement, some nationally, all locally. Hence my term 'top self-advocates'. Their life stories are not accounts of 'typical' self-advocates. The five narrators are high profile, experienced, articulate members of the movement, sharing extensive involvement with self-advocacy. Their stories are limited because they are not representative of the experiences of self-advocates at the morphological level, that is, the level of superficial description (Groce 1992, p175). However, following Corradi (1992, p112) and Humphreys, Evans and Todd (1987, p8), by scrutinising each individual story a number of general themes emerge that allow some insight into the lived experience of self-advocacy[7].

As Humphreys, Evans and Todd (1987, p8) concluded when commenting on the seven life stories of people with learning difficulties involved in the NIMROD services in Wales:

'While every description is very individual in nature, issues such as the struggle for basic rights as citizens can be seen in each account'.

The life stories will be used to draw out conclusions that reflect in a generalised form what in each document is expressed in individualised form (Thomas and Znaniecki 1918-1920, Corradi 1992, p110). Themes that emerge from one account will be scrutinised against other accounts (Corradi 1992, p112). Stories can contribute in some small way to an

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[7] As Bertaux-Wiame (1981) points out, stories from similar socio-structural backgrounds that support one another can be used to make a body of evidence.

understanding of a given network of social relations – self-advocacy (Bertaux 1981b, p40, Groce 1992, p175).

In the final analysis the stories can be refuted because they do not represent the experiences of all self-advocates with learning difficulties. Micheal Kennedy, a high profile and vocal American self-advocate, offers the following response to those who say he is not talking for all people with learning difficulties:

> 'When people tell me that I am 'higher functioning' than the people they are talking about, I feel like they are telling me that I don't have anything in common with other people with disabilities. It's like they are putting me in a whole different category and saying that I don't have any right to speak. It upsets me because I take it that they don't want to give anyone else the opportunities I have been given, and what I say they can ignore because I more capable.' (Kennedy 1997, p1)

The five life stories in Chapter 6 are not representative of all self-advocates' experiences[8]. They do, however, highlight some of the impacts of self-advocacy groups on the life experiences of a few.

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[8] How a 'typical account' is obtained is a difficult question to answer when people with learning difficulties, 'constitute a broad, heterogeneous group rather than a defined, bounded category of people, fixed within the parameters of statistical norms' (Angrosino 1994, p27).

Negotiating access with top self-advocates

Informants were contacted by telephone and letter (see *Appendix 3, 4*). Addresses and telephone numbers were obtained from a supporter with long-term involvement in the self-advocacy movement. Access was negotiated with reference to an introductory booklet (*Appendix 3, 1*). Following Barnes (1994), Simons (1994) and Walmsley (1995), the booklet introduced the research/er; explained how informants were contributing to the writing of a thesis and what would happen to participants' disclosures (life stories in thesis and published papers). Also explored was what both parties would get out of the research (submission of thesis for a PhD, copies of life stories for informants and hopes for publication of a self-advocate friendly report).

Research relationships are social relationships (Parker 1963, Oakley 1981, Sparkes 1994, Bannister et al 1994). Inequalities structured around gender, race, sexuality and disability enter the research context. Disclosing my involvement as a volunteer to a self-advocacy group appeared to encourage acceptance[9]. Also discussed was confidentiality (only I would see the transcripts) and the need to preserve the anonymity of others (because they had not been asked). Initially, all five were proud to have their names to their life histories. Later, 'Phillip Collymore' was to choose this pseudonym (see *Appendix 3,7* and Chapter 8).

Interviews

Informants were asked for their 'life stories'. Anecdotes were presented

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[9] As Anya Souza put it, she 'didn't mind my sort'.

chronologically, thematically and interspersed with opinions. Asking for stories, rather than experiences, may have invited expression (Reason and Hawkins 1988, p100). Interviews varied in length from about an hour and a half (Lloyd Page and Phillip Collymore), through to two (Jackie Downer), four (Anya Souza) and five hours (Joyce Kershaw). Total contact time was longer. Interviews were carried out in a variety of places, at home, in restaurants, cafés and in a group office (see *Appendix 3, 7* for details of meetings). Audiotapes and notes of interviews were transcribed, written up as stories, and first drafts sent to narrators. All five changed the first drafts, a number of times in some cases, until eventually accepting the finished life stories presented in Chapter 6. In some small way these experiences build upon literature about interviewing and narrative inquiry with people with learning difficulties (see Chapter 8 which follows up the research stories of collaborative narrative inquiry).

Analysis of life stories

Chapter 7 explores what the life stories reveal about the lived experience of self-advocacy. Plummer (1995, p62) asserts that there is much to be gained from the use of life stories. They take seriously the subjective dimension of lives, enable lives to be placed in a fuller social context and acknowledge the narrative nature of human conduct. However, are these gains the product of the life story alone, or do researchers need to intervene to broaden the gains? Answers to these questions may be split into two camps.

Arguments for analysing stories

'In the course of the critical review of the interface between life events and their personal interpretation, the researcher comes to

understand the individual in a way that the individual him or herself probably cannot (Whittemore, Langness and Koegel 1986, p7).

The meanings of a narrative arise out of the interaction of story, storyteller and audience (Reason and Hawkins 1988, p86). What audiences do with stories is often unclear. Consequently, an argument may be made for analysis that points out to readers themes within stories. Goodson (1992) suggests that analysis should increase the wider benefits of narratives by opposing unsympathetic, conservative or hostile readings. Analysis attempts to throw into sharp relief a range of structural constraints that shape narrators' lives (Sparkes 1994, p165). The emic view of the narrator and the analytical and reportorial skills of the researcher are combined to draw out broader socio-structural, cultural, political and theoretical points (Whittemore, Langness and Koegel 1986, p7). For example, Levine and Langness (1986, pp192 -205) concluded that the narratives of people with learning difficulties demonstrate a number of things; people so-labelled constitute a heterogeneous group, learning difficulties is socially constructed and people have competencies which are often ignored. Drawing out points of convergence in a number of stories shows the relevance of a few accounts to many similar others (Denzin 1970, 1992 cited in Hatch and Wisniewski 1995b, p126). Stories cannot stand alone (Kidder and Fine 1997). Analysis strengthens stories.

Arguments against analysing stories

'The problem of analysis is hence the extent to which the researcher progressively imposes his or her 'theory' upon the understandings of the participant' (Plummer 1995, p61).

If stories constitute 'the perfect sociological material' (see Shaw 1931, Thomas and Znaniecki 1918-1920) then why analyse them? Analysis theorises over the stories of oppressed people, takes away ownership and places abstract interpretations on personally significant stories (Friere 1970). Simone Aspis (1997), formerly Campaigns Officer for *People First London*, argues that when researchers draw conclusions from the stories of people without learning difficulties, then stories become secondary to researchers' 'expertise' (see also Whittemore, Langness and Koegel 1986, Goode 1992). The subversive character of stories should not be underestimated. As people re-write their own stories this constitutes an important political step forward (Williams 1989 p225, Humphreys, Hill and Valentine 1990), as narratives extend each reader's sense of what it may mean to be human (Turner 1991, p230). Allport (1947, p40) argues that social progress may come about through the employment of vivid stories of personal experience, - just as it came about through socially-orientated novels of the order of Uncle Tom's Cabin, Oliver Twist and The Grapes of Wrath. For Bertaux (1981b), life stories constitute an excellent discloser of underlying socio-structural relations and clarify decontextualised abstractions of structuralist theories (Sparkes 1994, p178). Proponents in this camp conclude that analysis is an unnecessary preoccupation of researchers.

Analysis as an aside and addition to stories

'The best stories are those which stir people's minds, hearts, souls and by doing so gives them new insights into themselves, their problems and their human condition. The challenge is to develop a human science that more fully serves this aim. The question then is not, 'is story-telling science?' but 'can science learn to tell good

stories?'' (Mitroff and Kilman 1978, p83).

The arguments presented by both camps are accepted in this thesis. Life stories stand alone in Chapter 6 and can be viewed without reference to Chapter 7, which explores my reading of what I think can be learnt from the stories about being in self-advocacy groups. The nature of my commentary is twofold. First, analysis is story-driven. Themes that emerge in stories will be used to make sense of the lived experience of self-advocacy, in turn highlighting points in the literature associated with self-advocacy and the social model of disability. Second, this literature will be used to highlight anecdotes in the life stories.

From narrative inquiry onwards

Narrative inquiry delves into the meanings held by narrators. Experienced activists reflect upon the past. In the final empirical study, section 4, the appraisal of self-advocacy continues to delve into meaning through engagement with self-advocacy's insiders. Section 4 aims to delve into the diversity of groups within the movement whereas section 3 represented the accounts of members of *People First*. Attention is turned away from life as narrative to life as process and action, from stories of narrators' individual self-advocacy, to ethnographic accounts of collective self-advocacy groups in action.

Section 4 - Self-advocacy groups in action

Section 4 addresses how self-advocacy groups work, how they are organised, what processes occur, what support is offered and explores further what self-advocates get out of involvement. A methodology was

needed that dealt with the qualitative richness of group dynamics, to address self-advocacy in action. Ethnography appealed. Below, ethnography is introduced and a number of strengths and limitations identified. The ethnographic study of four self-advocacy groups will then be presented.

Life through ethnography

Ethnographic study has been used to examine the processes and actions in various social contexts (Edgerton 1967, Marsh, Rosser and Harré 1978, Spradley 1979. Edgerton 1976, 1984a, 1984b). Ethnography is a useful technique for discovering beliefs, practices and meanings within a culture. Social settings can be seen as having cultures - a set of traditional ways of acting, feeling and thinking (Edgerton 1984b, p501). To get at these cultural artefacts, ethnography employs a whole host of qualitative methods, including participant observation (Marsh et al 1978), in-depth involvement (Edgerton 1984b), interviews (Spradley 1979) and story collection (Angrosino 1994). In this thesis, the ethnographic project relied mainly on participant observation and qualitative description in field notes, although group discussions were conducted later. The form of observational method adopted in ethnography involves more than simply observing a social context. It requires interaction with a social group, becoming part of the group's processes, to understand the symbolic nature of meaning within social action (Sidell 1993, p109).

Strengths of ethnography

A bottom-up and grounded appraisal

The ethnographic study in this thesis aims to ground understandings of self-advocacy in the actions of insiders with learning difficulties (Becker 1963). Ethnographers attempt to grasp the native's point of view, their relation to life and to realise their vision of their world (Edgerton 167, p84; Edgerton 1984b, p498 following Malinowski 1922). This involves getting to know people by being there, alongside them, during ordinary days, to try and capture their experiences at first hand (Atkinson, 1993b p59). Corbett (1998) describes ethnography as an immersion within the deep culture of a social group that attempts to find hidden treasures and submerged dangers. In theory, ethnography is committed to representing the actions of insiders, in this case, self-advocates and their supporters in self-advocacy groups.

Ethnography has been used in studies that have tried to ground their analyses in everyday realities of social groups (e.g. Lincoln and Guba 1985, Erlandson, Harris, Skipper and Allen 1993). These studies can also be seen as examples of 'bottom-up' research (Atkinson and Williams 1990). According to Spradley (1979) ethnographic study aims to observe behaviour, but goes beyond it to inquire about the meaning of behaviour. The artefacts and natural objects of a culture are described but also considered in terms of the meanings that people assign to these objects. These 'grounded theory' analyses start with data and remain close to data (Glaser and Strauss 1967, Lofland 1971, Charmaz 1995). Moreover, emotional states are observed and recorded, but the ethnographer goes beyond these states to discover the meaning of fear, anxiety, anger and other feelings to cultural members. In theory, then, ethnography's links with

grounded theory and bottom-up analyses fit the aims of examining self-advocacy in action from the inside.

The study of 'new social movements'

Ethnographic study appears to lend itself to the study of new or marginalised cultures. First, ethnography provides a technique for studying those groups that in some ways run counter to the larger institutional culture (Edgerton 1967, 1976, 1984a, Edgerton and Bercovici 1976). Understandings of action 'known' in dominant institutional practices may be re-appraised through immersion in settings that are different, other and subversive. Second, ethnography appears to suit the study of 'new social movements', wherein we could place self-advocacy, as part of the 'new' disability movement (Shakespeare 1993b, Campbell and Oliver 1996, Bersani 1996). Knowledge can not only illuminate the lived experience of progressive social groups but also be illuminated by the struggles that occur in these groups (Lather 1986, p262).

Ethnography and empowerment

The ethnographic enterprise addresses a number of issues associated with empowering research. Walker (1981, p148) suggests that people rarely emerge from studies as people with their dignity intact. Proponents of the social model of disability have drawn attention to research that is grounded in the experiences of disabled people (see Chapter 3). Ethnography appears to offer a method for considering participation and praxis. First, gaining access to new cultures requires couching research aims in accessible ways that are appropriate to that culture - participatory methods (see Bashford, Townsley, and Williams 1995). Second, being let into a culture for an

extended period of time increases expectations of reciprocity where participants getting something out of research (see Reason 1988, Reason and Hawkins 1988, Reason 1994). In-depth involvement requires a re-framing of the research exercise (Schatzman and Strauss 1973).

Reflexivity

Ethnography requires outsiders to formulate understandings of insiders that are in tune with the interests of the research population as well as those of the researcher (Peberdy 1993, p54). Consequently, Halfpenny (1984, pp3-8) suggests that researchers should show how their interpretations are bound up in the study of a culture by detailing descriptions of activities, verbatim accounts of talk, key illustrations of their interpretations and a chronology of research experience. In doing so, a reflexive account can consider in some ways the interplay between the researcher's subjectivity, experiences in the culture and the analyses that are made. Chapter 11 considers reflexivity.

Limitations of ethnography

Seeing what you want to see

The hallmark of ethnography and grounded theory consists of the researcher deriving his or her analytic categories directly from the culture under investigation, not from preconceived concepts or hypotheses (Charmaz 1995, p32). Theories, models and typologies must be teased out of an immersion within a social grouping (Harré 1981, Bannister et al 1994, p74). However, as Glaser and Strauss (1967) pointed out, qualitative methods are impressionistic and unsystematic. All descriptions are

analyses. As method and analysis work from one another, in a hermeneutic-dialectical fashion (Erlandson et al 1993), the researcher's own analytical ideas become tangled up in description and analysis. Consequently, researchers may only see what they want to see. For example, Gerber (1990) appraised Edgerton's (1967) ethnographic study of people with learning difficulties in institutions[10]. While acknowledging Edgerton's compassionate appeals for re-assessing how institutions stigmatised 'the retarded', Gerber suggests that Edgerton's naturalistic view of retardation lurked behind the stories of those he presented[11].

Consequently, the resilience of those who had been institutionalised was only partly highlighted because Edgerton's analytical framework failed to recognise the socially constructed nature of learning difficulties. During ethnography I saw things that I did not expect to see. However, as much as I tried not to place a priori concepts onto the data, my subjectivity directly affected the ethnographic findings. For example Chapter 10 tries to make sense of advisors' support as interventions or actions which can be seen as reflecting discourses of disability. I had started to formulate this analytical framework during my involvement with groups. As much as I made conscious efforts not to, my observations were in part directed by this framework in mind. Schatzman and Strauss (1973, pp99-103) acknowledge that ethnographers will inevitably combine 'observational notes' (the who, what, when, where and how of human activity) with 'theoretical notes' (interpretations, inferences, hypotheses and conjectures) and 'methodological notes' (the timing, sequencing, stationing, stage setting and

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[10] See also Edgerton (1976) and Edgerton and Bercovici (1976) for follow up studies.

[11] Luckin (1986) provides another critique of the 'Cloak of Competence'.

manoeuvring of research). Indeed they go further and say that the 'model researcher starts analyzing very early on in the research process' (p110). Chapter 11 considers some of the dynamics between my observations, experience, subjectivity and analysis.

Only seeing what groups want you to see

Beresford (1992, p24) approached a self-advocacy group to ask if they would help him with a handbook on user involvement. One member was bothered, 'If we talk about how we do things, if that's written down, then services who want to will know how to block us'. Participants may 'act up' for observers so as not present themselves in a bad light (Orne 1962, Swain 1995). Such impression-management is understandable if Barton's (1996) observation is a fair one - that most sociological appraisals tend to look for failings in the social world. Observations are further problematised when they are a researcher's biased observations of unnatural and contrived behaviour. Moreover, complicated events are often simplified when observations are written up as field notes (Walker 1981).

Ethnography changes contexts

When social contexts become research contexts they are changed (Parker and Shotter 1990). Researchers become part of the cultures that they describe, and researcher and participants interact to produce the data (Charmaz 1995). One example of this in my ethnography was when I tried to take a 'back seat' in meetings but was seen by a number of self-advocates in one group as a 'helper'. While I continued to try and negotiate myself a position outside of the context, I was actually part of the context (this is followed up in detail in chapter 11). Ethnography's involvement

with a social context changes it into a research context, making the representation of naturally occurring behaviour seem impossible.

Doing ethnography : self-advocacy in action

Questions remain over whether or not ethnography can fully grasp the meanings and processes inside self-advocacy groups. However, while accepting the limitations, in this thesis the ethnographic study is my appraisal of a number of groups, at specific times, in particular contexts, where I have tried to authentically capture some of the experiences of a few self-advocates and their supporters.

The four groups

The four groups at the centre of ethnographic study in this thesis reflect some of the different ways in which self-advocacy groups are organised. They are not, in the positivist sense of the word, 'representative' of the movement. Only so many groups could be studied in an in-depth, involved and qualitative manner over 14 months. Attempts were therefore made to capture some of the specificities of self-advocacy. Specificity acknowledges the mutable nature of social life (Hisada 1991, Bannister et al 1994) and recognises that research studies are of a particular time carried out in specific contexts. I aimed to build up rapport, familiarity and trust. Four groups appeared manageable. It was hoped that the four groups in this study would provide rich enough specific contexts to:

> 'Analyse the specificity of mechanisms of power, to locate the connections and extensions in order to build, *little by little,* a strategic knowledge' (Foucault 1983, p197, italics in the original).

As Chapter 2 outlined, two main areas of self-advocacy have been used to distinguish between groups. First, *group types* have been identified that differentiate groups on the basis of their accountability to and relationship with other organisations. These include independent, divisional, coalition and service-based types (Crawley 1982, 1988, 1990, McKenna 1986, Simons 1992, Dowson and Whittaker 1993). Second, *status of advisors* has been used to discriminate between groups. Advisors can be independent, service-based or have ties with divisional or coalition groups, and may offer their services voluntarily or as part of their jobs (Hanna 1978, Worrel 1987, 1988, Clare 1990, Sutcliffe 1990, Sutcliffe and Simons 1991, Simons 1992, Dowson and Whittaker 1993). Four groups were chosen from the questionnaire responses because they reflected various group types, encompassed different advisor positions, and were accessible in terms of distance:

- *The 'Centre Group'*

This is a Centre's working group that aims to represent all users' concerns. 10 members are voted in by Centre 'users' and meet weekly for two hours in a room in the Centre. Support comes from a paid staff advisor who supports the group as part of her job. A number of members also attend a local monthly advocacy development project meeting. Financial support comes from the Centre. No major funding is required for transport or the hiring of rooms because meetings are Centre-based.

- *The 'Social Group'*

This group meets at a local social club for two hours every three weeks.

Advisors with independent and service affiliations voluntarily support 15. Advisors include a key-worker, a centre manager, a retired social services employee, an advocacy project development worker and an employee from the local train station. The group functions as an informal get-together, though a number of members also attend conferences, workshops and formal 'consultation' meetings with local authorities. The group is funded through small-scale fund-raising activities and 'handouts' from local businesses.

- *The 'Advocacy-supported Group'*

Meet monthly in the premises of a youth club with support coming from a volunteer, independent of services, and two advocacy workers who support the group as part of their jobs. All 14 members recently lobbied the local council about the state of roads in their village. Members are also involved in a number of projects set-up by the advocacy organisation. Members pay 'subs' for the use of the room and carry out their own fund-raising.

- *The 'Independent Group'*

This group has their own office. Funding comes from the County Council who offer the group as an alternative to local day centres. Three independent supporters are paid by the group out of funds to support between nine and 12 members. The group provides training programmes for a variety of organisations, which they get paid for. Separate management and executive committees meet up, though the office is open throughout the week as a 'drop-in' centre for people with learning difficulties in the locality. The group has links with organisations of disabled people.

These groups reflect some of the complexities behind the 'types'. For example, the Independent Group may on the surface be deemed an 'autonomous' type. However, the financial input of the county council and the way in which the group is offered as an alternative to Day Centres, brings in 'service-based' affiliations. Generally, the four groups have apparently internal contradictions and overlaps of 'type' and 'advisor status'. It was decided that they would be useful collectives within which to examine the elaborate nature of self-advocacy in action.

Gaining access to groups

May (1995) distinguishes between physical and social access. Physical access begins with initial contact and concludes with the beginnings of involvement. Groups were contacted (between September 1995 and April 1996), referring to telephone numbers on questionnaires, and introductory meetings were arranged. All group contacts (three of which were advisors, one a self-advocate) consulted group members before agreeing to our first meetings.

Social access involved pro-longed and continuous negotiation of my involvement with groups. Three groups addressed my interests at the first meeting. Two found places for me on their agenda and another gave over the floor to a self-advocate who presented a 20 minute introductory account of the group. For the Social Group, it was not until the third meeting that I decided that I should formally and publicly introduce myself to all members, as opposed to some individuals.

Groups were reminded of the questionnaire that I had sent some months back and told of my ambitions to 'sit in' groups to see how self-advocacy

groups work. The main reason for my interest was disclosed (my PhD research, 'A posh name for a qualification') as was my involvement as a volunteer to a self-advocacy group. I explained that I wanted to take a back seat and learn from them about self-advocacy in action. This back seat role was open to change and re-negotiation (see Chapter 11).

To facilitate access members, were presented with and taken through an introductory booklet that combined prose and pictures (*Appendix 4, 1*). Members appreciated the use of pictures because it appealed to 'non-readers' and was similar to the format that they use in their minutes. Others picked out illustrations as we went through the booklet, 'Is that you Danny?', 'Is that you pointing to us, the group?'. Some members asked me to go through the booklet with them individually at later meetings. In addition, attempts were made to use terms chosen by groups in the introductions. This is what Goode (1992, p208) terms 'emically informed language', like 'talking out' if the group used that instead of self-advocacy, or 'supporter' instead of advisor.

Members and advisors were instrumental in tackling the initial stages of social access. For example, after going through my introductory spiel, the chairperson of the Centre Group (a self-advocate) told me, 'Thank you Danny. You can go now. It was nice to meet you as a friend and a person'. I was then led out of the room so that the group could decide whether or not they wanted me to attend subsequent meetings. At another introductory meeting a chairperson asked everyone to introduce him or herself. I left a quarter of an hour before the end so that the group could have a chat about my research.

I found it helpful to take cues from advisors. Once I was struggling to

explain myself, 'I want to see ... how ... groups ... eh, work'. An advisor stepped in; 'Do you mean you want to sit in our group?' (Advocacy-supported Group). Another advisor clarified the stages of my research, 'Can you remember when Danny sent us that questionnaire, well now he would like to see how we do things in more detail' (Social Group).

Acceptance in groups and contact time

The amount of contact time with groups depended on how often groups met up and what they deemed a fair amount of involvement. Two groups met for two hours every three weeks (Social and Advocacy), one got together weekly for two hours (Centre) and another had one main designated drop-in day per week, along with monthly executive and management meetings (Independent). Travelling to groups was time-consuming - a six hours round journey (including meeting time) was required for the Social Group. Groups were spread over three counties and four separate local authorities were represented in the services used by self-advocates in this study. Contact time was as follows:

• *Centre Group* (April 1996 - November 1996)
Six meetings were attended and contact was had with group members outside of meetings in the Centre. Contact time around 24 hours.

• *Social Group* (November 1995 - January 1997)
Nine group meetings, one 'user consultation meeting' called by the local authorities (attended with a number of group members) and time spent with members before and after meetings. New Year 1997 was celebrated at a local restaurant. Total contact time around 27 hours.

• *Advocacy-supported Group* (May 1996 - November 1996)

Six meetings were observed, time before and after meetings was used to chat with members and the local advocacy project AGM was attended along with a number of the group members. Contact time was 18 hours approximately.

• *Independent Group* (November 1995 - September 1996)

Eight trips to the group's office where various members dropped-in. Time spent with members preparing agenda, discussing training and chatting about this and that. Trips out shopping, to the bank and helping the group move into new office premises. One executive committee meeting was also sat in and a meeting was held with representatives from the County Council with members of the executive committee. Contact time was approximately 23 hours.

Methods

Observational field notes were made after all meetings (audiotaped and written up). These consisted of reflections, personal feelings, hunches, guesses and speculations as well as observations and vignettes of actions and conversations (Bannister et al 1994, p23, Schatzman and Strauss 1973, pp99-103). Such qualitative description and analysis highlighted a number of concerns associated with my subjectivity. This emerged as a separate point of analysis (see Chapter 11). In addition, groups' own documents were gratefully received. These included outlines of group histories (all groups but Centre), group constitutions (Social and Independent), minutes (all groups), details of local advocacy forum (Centre), invitations to and details of outside meetings (Advocacy and Social), training documents and introductions (Independent).

Group discussions were carried out in order that members had their say and to formally close my involvement. Introductions to group discussions were made with reference to a booklet (*Appendix 4, 2*) and a list of questions and prompts were brought along to sessions (see *Appendix section 4, 3*). Sessions varied in time from 15 minutes (Social Group) through to two hours (Centre Group). Three of the group discussions had advisors present, the Centre Group had only members. Written notes were taken and later written up, combining pictures and prose, as feedback reports for each group. These were read through by groups and advisors, alterations were made, producing the reports presented in *Appendix 4, 6 - 9*.

Finally, groups had a number of requests. The Independent Group had been asked by their main funding body the County Council to find an independent person who could evaluate their project. The group put my name forward. I attended a meeting along with representatives of the County Council and the Independent Group's chair, vice-chair and a supporter. Later, I had another meeting on my own with one of County Council representatives to talk about the evaluation report that I was to write for the group. The major source of the evaluation were members' comments gained at the group discussion (see *Appendix 4, 9*). I was also asked by the County Council to canvass the views of some organisations that have received training from the Independent Group. An evaluation report was written up and presented to the County Council (see *Appendix 4, 11*). A different format of the same report was sent to the group (*Appendix 4, 10*). Other requests a re-write of the constitution and introduction for the Social Group (*Appendix 4, 12*) and, following discussions with the Advocacy-supported Group, a leaflet on voting was posted to all four groups (*Appendix 4, 13*).

Analysis of Ethnography

Analysis is approached in three ways in order to make sense of the group processes in self-advocacy groups. Chapter 9 describes the dynamics of each group. Then, working from a grounded theory approach, ethnographic material obtained from each group is used to test out 12 points about 'self-advocacy groups in action' that emerge from previous literature and from the groups themselves. Chapter 10 delves deeper and more specifically into group processes by considering how self-advocates are supported in the context of the group by advisors and peers. With reference to the observational notes, the analysis becomes more theoretically driven as models of disability are employed to make sense of incidents of support observed in the ethnographic study. Finally, in order to address the subjective bent of these analyses, Chapter 11 considers how the ethnographic exercise and my experiences as a supporter in a self-advocacy group informed subjectivity and analysis.

Conclusion

This chapter has introduced the methodologies, methods and analyses employed in this thesis to appraise different elements of self-advocacy. While not flawless, the postal survey, life stories and ethnography are considered to be useful tools for examining the contemporary self-advocacy movement, the impacts of self-advocacy group membership on life experiences and the process in self-advocacy groups. The next section of the thesis investigates the findings from the postal survey.

Section 2

The Nature of the Contemporary Self-advocacy Movement

Chapter 5

Findings from a postal survey of self-advocacy groups

Introduction

In 1992 Simons estimated that there were approximately 500 self-advocacy groups in the UK (Simons 1992). This chapter presents the findings from a postal survey of 134 groups in the UK. The analysis is split into three sections. First, the responses to each item on the survey are summarised. Second, a thematic analysis of group discussion topics (item 8) is presented. Third, the responses from the 134 groups are analysed to see if they fit the typology of groups identified in the literature (*People First of Washington* 1984, Crawley 1988, 1990, Simons 1992). In conclusion, it would appear that the movement's heterogeneity counters the imposition of classifications and categories presented in the literature (e.g. Hanna 1978, Worrel 1987, 1988, Sutcliffe 1990, Crawley 1990, Flynn and Ward 1991, Simons 1992, Dowson and Whittaker 1993, Downer and Fearns 1993). While this postal survey provides a useful account of the movement's complexity, questions remain about the life experiences and actions that go on under the banner of self-advocacy.

(1) Summary of responses to each item of the survey

Responses to each item of the survey were coded and summarised using SPSS (see *Appendix 2, 5* for coding schedule).

Item 1 - What is the name of the group?

The banner of self-advocacy encompasses many labels.

Table 1

% of groups	Group Name And details
38.3	*People First* groups (e.g. Madeuptown People First)
11.9	*Committees & councils* : student, consumer, client, user or member / committee, council or group
11.2	*Self-advocacy* groups (Self-advocacy in action)
10.4	Names that Centre around *'Speaking'* (Speak & Listen, Speaking Out)
9	Groups with *atypical and unusual names* (Act it Out Work it Out, Friends, You, me and us, Daffodils, Myself & Others, Progression, Reflected Images, Our Vision, etc).
4.5	Names acknowledging *Residential* base (Residents group, Tenants committee)
3.7	*'Named'* groups (Madeuptown Centre group, Karl Marx group)
2.2	*Women's* self-advocacy groups

Continues over ...

2.2	*Community initiatives.* (Community Partners / Action)
2.2	*Advocacy without the self* e.g. Madeuptown advocacy group.
1.5	*Committees* and *councils outside of services* (MENCAP consultative / management group).
1.5	Groups without a name (Don't know yet, To be decided).
0.7	*Men's* self-advocacy groups
0.7	*Black* self-advocacy

Item 2 - Who are the group members?

Self-advocates / members with learning difficulties:

- 36% have less than 10,
- 45% have between 11 and 16,
- 12% between 20 and 100,
- 7% have large numbers (from 200, 500 through to 'lots').

Staff supporters:

- 32% have no staff,
- 52% of groups report the involvement of one or two,
- 22% have between three and nine.

Parents:

- Nearly all (126 respondents giving information) have no *parents* in their groups. One group has one parent, another 12 and a final one 15.

Other members:

- included 'advisors', 'invited guests', 'other self-advocacy groups' and a 'member advisor'.

An aside to item 2 was whether or not advisors, supporters and parents were seen as group members. In 12% of responses, advisors / supporters were not counted as members of the group in response to item 2, even though they were mentioned later in the questionnaire.

Item 3 - How often do you meet?

- 10 groups meet twice or more a week,
- 38 weekly,
- 30 fortnightly,
- 6 every three weeks,
- 44 monthly,
- 5 every two months.
- One group reported split times - committee meetings every two months and an informal get-together in the week.

Item 4 - Where do you meet?

Some groups may meet in a variety of contexts but cited the one they met in most often:

Table 2

Meeting place(s) and details	% of gps
Centres : Social Education & Adult Training Centres, Resource Centres, Colleges.	34.8
Rooms away from Centres e.g. Church halls, Convents, YMCA, Labour Clubs, Council room, town hall, leisure Centres, Pubs, cafes.	31.1
Independent organisations e.g. Citizen advocacy, Disability consortium, Organisation of disabled people, Skills for people, Women's Centre, Spastic Centre (sic)	15
Own office independent of Centre e.g. People First office	8.3
Meetings in members home / place of *residence* e.g residential unit, hostel	4.5
Office of large *charity* organisation e.g. MENCAP office for management committee	2.3
Groups meet in their *own room* in a Centre	1
Group meets as part of Mental Health *Initiative*	1
Get-togethers in 'therapeutic *villages*' for people with learning difficulties	1
Meetings *split* between Centre and room outside	1

Item 5 - How long has the group been running?

Information received from 123 respondents:

- 19% have 'just started' or are have been going for a year or less,

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- 30% are between 3-4 years old,

- 28% 4-5 years,

- 19% 6 - 9 years,

- 4% are celebrating being around for a decade or more (oldest 15 years).

Item 6 - Describing the advisor

96% of groups have advisors and categorised them in a number of ways. Choices provided for item 6 were 'parent', 'member of staff' or 'other', though descriptions were often elaborate.

Staff

The response of 'staff' was evaluated alongside other information given on the questionnaire to assess for service links. Not enough information was provided by 9% of respondents to ascertain the description of the advisor.

Table 3

Advisor Description	% of gps
Members of Staff *'College and Centre staff', 'assistant senior social worker', 'staff 'facilitator'.*	35.3
Member of advocacy / coalition *'support worker from community forum / skills for people', 'advocate'*	22.4
Independent People *'independent facilitator', 'independent advocate', 'freelance advisor'*	13.4
Co-ordinators *'Co-ordinator advocacy org.', 'Full time salaried project co-ordinator'*	3.7

Continues over ...

Supporter managed / employed by group 'self-employed advisor recruited on sessional basis', 'We employ our own advisor' .	3
Volunteers supported by advocacy organisations & advocacy workers e.g. 'volunteer advisors are not paid, supporters are'	2.9
MIXED Staff members and volunteers : 'one volunteer and one social worker'	2.2
Staff members and Advocacy support : 'staff & self-advocacy worker'	1.5
'Many advisors' : 'Council voluntary service workers, MENCAP and citizen advocacy organisations'	1.5
Staff and members with learning difficulties	0.7
Co-ordinator and People First supporter	0.7

Others?

46% gave details about 'others' in considering the advisor role:

- 23.1% mentioned advisors and support workers (facilitators, supporters, helpers, supporters and advocacy workers).

- 13.4% cited helpers and volunteers (minibus drivers, *People First* enablers),

- 5.2% included guest speakers and other groups (students and guests, police, placement officers, invited guests, management committee),

- 2.5% offer an open invitation to trainees and 'clients' from (other) day Centres,

- 0.7% invite new members of staff along, 0.7% carers and 0.7% Centre managers.

The status of advisors

Responses were coded to consider the paid / voluntary and staff / independent status of advisors. Supporters were classed as voluntary even when groups covered their expenses. 'Paid' supporters receive a salary. 8.2% of respondents did not give any or enough information about their advisor, 3% said they did not have an advisor.

Table 4

Advisor Status	% of gps
Paid Staff - self-advocacy as part of staff members' job. *e.g. Self-advocacy workshop running in Centre as part of curriculum*	29.3
Paid Independent(s) – independent advisor paid to support group (i.e. workers from MENCAP, citizen advocacy, Independent Living organisation, Disability Coalition) *e.g. As part of a county-wide advocacy project, three workers from the project set-up and support a self-advocacy group that meets in a local church hall*	26.9
Voluntary Independent(s) -Independent person / people offering support voluntarily. *e.g. A student is accepted by a local group as advisor*	11.9
Voluntary Staff – self-advocacy is offered by a staff member voluntarily. *e.g. A careworker from the Centre supports a group that meets in the local pub in his / her own time*	6.7
Paid (by group) Independent(s) - the group pays independent person(s) to be their advisor *.e.g. the group receives money from a charity and employ a support worker to help them in their activities*	5.2
Paid Independent(s) & Voluntary Independent(s) *e.g. Workers from an Advocacy organisation plus volunteers, support a group for women with learning difficulties*	3.7

Paid Staff & Voluntary Independent(s) *e.g. A key-worker supporting a 'trainee committee' enlists the help of an interested student from the local University*	1.5
Paid Staff & Paid Independent(s) *e.g. A tenants group are supported by one of the staff members in the house and an outsider from the local advocacy project*	1.5
Paid Independent(s) & Paid by group Independent(s) *e.g. A self-advocacy group has just moved into their own offices. Their two employee support-workers (financed through donations from charities) are joined by an advocate from the local citizen advocacy offices, in helping the group to increase its independence*	0.7
Paid Staff & Voluntary Staff *e.g. A key-worker facilitates a self-advocacy forum as part of the Centre curriculum. An interested social worker comes in in their own time to offer further support*	0.7
Paid Staff, Paid Independent(s) & Paid by group Independent(s) *e.g. A working group in a day Centre is facilitated by one of the care-workers. In addition members also meet on Wednesday night and are supported by a worker from the local advocacy*	0.7

Item 7 - Roles and rules in groups

Some insight was gained into the structuring of meetings.

- 77% of groups responding have a *chairperson*,

- 58% a *secretary*,

- 96% a *treasurer*,

- 80% take *minutes* of meetings, 84% keep an *agenda*,

- 80% have elections for posts within the group,

- 40% hold elections to decide if new members can join.

Some respondents cited their advisors as treasurer (2 groups) and secretary (1 group). Others 'rotate' roles for each meeting with self-advocates taking turns.

Item 9 - Support and funding

As anticipated a number of groups refrained from giving details of their funding. Seven groups ignored the question altogether, others were vague. The majority (126) gave some details and mentioned a number of sources:

- 50 % cited *local authority* support,
- 19% *health authority*,
- 75% receive *charity* money and,
- 32% saw themselves as *self-funded*.

When asked about any 'other funding', of those that responded:

- 65% mentioned 'many sources' (e.g. subs, local money, MENCAP, raffles, advocacy support),
- 8% acknowledged service support (e.g. 'Centre funds our conferences', 'Our day Centre helps', 'local authority', 'health authority'),
- 6% Advocacy organisation support (e.g. 'Agency assists'),
- 6% gave examples of fund-raising activities (e.g. 'subs', 'raffles', 'sponsored silence', 'money we got from sale of our 'Start!' video - Video made by group on how to set up a self-advocacy group),
- 5% gave details of charity support (e.g. 'MENCAP', 'Charity pays for our advisor', 'Applying for money from National Lottery'),
- 3% said they receive grant awards and 1% told of parents and carers donating money.
- 3% said they receive donations from local firms and businesses,
- 3% announced direct support from policy initiatives (e.g. 'county planning team support', 'All Wales strategy', 'Department of Health'),

Sometimes respondents did not consider funding with respect to the group's advisor. Consequently an additional source of funding was coded:

Table 5

% of groups	Description of funding sources with respect to the group's advisor(s)
31	*Service support* The group receives funding indirectly from local authority / health authority / social services, etc. when one or more of the advisors is a staff member and their support is part of their job *e.g. A social worker at a Social Education Centre starts up a workers' committee*
31	*Independent support* The group receives funding indirectly from various independent organisations / advocacy projects / MENCAP, etc. when one or more of the advisors supports the group as part of their job *e.g. A worker from citizen advocacy spends a day of her working week supporting a self-advocacy group in a group home*
25	*No funding for advisors* The group receives no indirect funding as their advisors are voluntary or the group pays for their support themselves out of existing funds *e.g. A group receives a grant from the local authority. They decide to pay for an advisor themselves*
2	*A combination of 1 and 2* Independent and service support through the paid independent and paid staff supporters.
11	Not enough information given

It would appear that advising self-advocates is a growing industry with financial support coming from numerous sources.

Comments from respondents about the questionnaire and survey

37% of respondents offered further comments, a selection of which are presented below:

> Thank you for sending me this form it was easy to read with the symbols. Pictures are very good would you like us to send you our newsletter? We like your form! It was really interesting do this questionnaire. We appreciated the symbols - our agendas, etc. are all written in words and 'Total Communication' symbols. The group thinks that it's a good idea and your form is well presented. Thank you for sending us this letter. Wishing you all the luck with your survey. It is always good to see someone taking an interest in advocacy.

Similar to previous attempts, accessibility was appreciated (see for e.g. Marsh 1992, Taylor and Bogdan 1984 pp91, Minkes et al 1994, Simons 1994, Walmsley 1995). A number of groups offered invitations for me to visit them or were accommodating in other ways:

> I enclose some information and if you require any help please do not hesitate to get in touch. Anyway we can help we will be pleased to do so. I hope this information will be of use to you. Any correspondence can be made to the facilitator. I have sent copies of the questionnaire to the 6 local groups - I hope they will reply to you. Constitution enclosed.

A number of groups had queries that were replied to:

> At the moment nobody [funds the group] we may close in September if our council does not give us any money. What are you going to do with the surveys? Can we have a copy of any report? Do you know where we can get any money? We would be interested in your findings. We would be interested to know what you do at college and what you will do with this information.

Attempts to make the questionnaire format accessible may have played a part in 26% of respondents being self-advocates alone. 40% were joint efforts between advisors and members. 34% were completed by advisors alone - a high percentage similar to Crawley's findings (Crawley 1988).

(2) What do groups talk about?

Respondents did not put down everything that they talk about in response to item 8. An analysis of the themes that were mentioned at least lends some insight into the prominence of particular topics in group discussions. A few respondents gave only general comments:

> We talk about all sorts. Any issues which tenants want to discuss regarding their lives at the Centre. Anything that concerns the members / clients at the Centre. Services / resources - in total confidence. Things they did before the meeting and things that they're going to afterwards.

One questionnaire (completed by a supporter) was convoluted and jargonised:

> 'Changing Policy. Hospital resettlement. National Health Survey. Staff change with no consultation. Unitary Authorities and the future after LGR. Reports from forum, joint secretariat. Funding (or the lack of it) AD INFINITUM'.

While another advisor was dismissive:

> 'In my experience most 'self advocacy' groups are no such thing! Ours is no exception. The only forceful corporate act of self-advocacy perpetrated by the groups is to force the volunteers into organising, leading type roles and to create the atmosphere of a social institution. It will take many years to challenge this model

successfully, although it is not as awful as many 'committee structure' groups'.

The majority of respondents were more forthcoming.

Sticking up for yourself and others and acquiring new skills

Was explicitly mentioned in 42% of responses, reflecting previous definitions of self-advocacy (see for e.g. Sutcliffe 1990, Flynn and Ward 1991, Simons 1992, Mitchell 1997):

> Working together, helping each other. Help the less able. Being diplomatic. Speaking up for ourselves and to each other. About us. Where to go for help if you are not happy. Independence and assertiveness. Helping each other to speak for ourselves. Assertiveness for social situations. How to stand up for myself. Changing people's attitudes. Stop people bossing us around. Not to let people put on us. About the future. Being more independent. Self-advocacy. Way of informing society about our needs and wishes. Main objective is to get out views heard. Goals and aims. getting the help you need. To talk. What to do if.

> We try things we haven't tried before. Karl and Jenny have just attended a self-advocacy workshop - we're going to meet to hear their ideas and what they did at the workshop. Person came in to talk about speaking up if you have a complaint. Video on housing, crossing the road, using the phone. Going through the new Open University packs. Communication. Problem solving. Road safety.

These comments support Atkinson and William's (1990) observation that self-advocacy groups support people with learning difficulties to share experiences.

Personal issues, relationships and fun

Were mentioned by 50% of groups:

> Problems we share (people calling names behind our backs). Meeting new friends. Building confidence. Things we feel good about, things we have achieved. I have a dream. Our worries and what to do. Favourite things. How we are interested. Feelings. Dealing with personal issues the advocates want to raise. What they want, how they feel.

Groups showed interest in wider social issues:

> Current affairs. World news - things that go in the world, today and tomorrow. Women's issues. Being a man. Disputes between service users. How to resolve problems. Role play bits of everyday life. Social and personal issues. Any problem trainees might have. Friendship, problems at home.

A number of respondents said they talked about relationships - an area of the lives of people with learning difficulties that is often ignored (Gunn 1990, Craft 1987, Oswin 1991, Booth and Booth 1994):

> Being married - girlfriends, etc. Abuse - self-advocacy as a subject, which applies to students. Boyfriends, girlfriends, family, children, sisters. Bereavement. Respite care - some people find it good, others don't. Women's issues. Bullying and abuse by residents and staff. Divorce. Loving other people.

Other people's needs were also represented ('Children running away from home', 'Other people who are not as well off as us'). One respondent's comments, who did not leave his / her name or address, highlights a contrasting side to the happy stories being told by groups:

> 'Sex / sexual worries. Unemployment / employment. Learning difficulties. Hobbies / Interest. Human body. Housing. Stand up

for your right. Girls / women re one. Socializing. I am a single man and I am very lonely man. Age 30. I need a woman / girl / female companion for sex and company. I have many problems. I love masturbation to ease my problems / pain. I would like women socialise I fell like killing myself. Please help me as I am having lot of emotional pain. Emotional pain (sic)'.

Leisure activities, outings and fun

Cropped up in 37% of responses:

All things to do with sport and Leisure. Coffee mornings, outings, holidays. fish and chip suppers. Drama, cooking, making cards, bowling. Painting. Christmas lunch and shows. Social activities - we always have a disco when we break up. Picnic, walkabouts and coffee. Cinema and theatre. Football, snooker and holidays. Holidays, acting, skittles and discos.

Worrel (1988) recognises that making decisions about leisure pursuits can bring out into the open the whole gambit of personal issues associated with competence, choice and 'user' involvement:

Whether you can go to the pub or not. How difficult it is to have social evenings without transport. Shopping. Organising outings - cinema and discos.

Running and progressing the group

40% of groups said they talked about planning meetings, trying to increase membership and writing reports. Running the group has many positive implications in building up the collective part of self-advocacy (Williams and Shoultz 1982). Considerations of group structure were evident, along with general day-to-day running, as were wider constitutional issues:

Getting a new supporter. Planning adverts. Should we have a chair in the meeting. Discussions regarding the group process, i.e. choosing chairperson. Elections. Committee members and their roles. All members should have a job to do. Ground rules, group structure. Election for chairperson. group membership, letters, [report] by chair. Getting new members in. Matters arising from previous meeting. Things they are going to do (sic). Membership, letters, chair. Sorting out the AGM. What the group should do. Treasurer report to collect the money. Whether to join *People First*. Setting up a summer social club. Whether to join in National events such as the MENCAP / Gateway Annual conference.

Extending group activities were also focused on:

Inviting people to talk, i.e. police, fire brigade, nurses, social workers. Feedback from other *People First* groups. Our Annual Conference. Looking for a new advisor. Interviewing a new advisor. Asking staff to come along and ask them questions. Follow up complaints from other users not on the committee. Meeting away from the Centre. Getting our own office. Planning for future development within the organisation. writing to the newspaper about new advisor. Hosting conferences. Setting up a women's group.

Formally advancing the group

Appeared as a distinct concern for 19% of respondents, sometimes presented in formal and business-like ways:

We give workshops on self-advocacy. Making the 'Start!' How to run a successful self-advocacy group' video. Setting up a 'Voice' independent voluntary organisation with charitable status Hopefully this group could be linked to the Open University Equal People course. co-ordinating the activities of many affiliated independent advocacy groups. Hosted conference on self-advocacy. Give feedback from all local advocacy organisations. Giving information

out about our group. Provide access to independent self-advocacy. Self-advocates and advisors are employed to develop self-advocacy in their localities. Enabling small groups to develop in parts of city. Working with advocacy organisation.

Centres

People with learning difficulties are talking about Centres in self-advocacy groups, independent of formal 'user consultation' meetings (30% of responses):

> Getting things for the Centre. New hammers / brooms needed in concrete shop. More new waste bins needed. Light not working, toilet seat broken, paper towels. Mainly to do with everyday matters concerning day Centre life. New things at Centre if doors need mending or tables. Suspension from day Centres. People's behaviour at day Centre.

While desired changes were articulated:

> Things that we want to do at the Centre and things we want to change. Anything that goes on at Centre, and what changes they would like to see and follow up complaints from other users not on committee. Name for new minibus. There is continuing concern at the amount of very unpleasant swearing. Running the Centre. Rules at the Centre. Deciding how money is going to spent at then Centre. About our industrial Centre. Going from Centre to college.

A bone of contention for a number of groups related to Centre charges imposed upon users (8%) and the lack or inadequacy of wages (27%) paid to users for work in Centres:

> Protests against day charges. The unfairness of having to pay to come to our day Centre. Opposition to day Centre charges. wages (incentives) in day Centres. Day Centre 'wages'.

Professional intervention

11% of groups mentioned professional roles and practices. This echoes recent *People First* reports, where people with learning difficulties are actively questioning professional practice (e.g. *Oi! it's My Assessment, Helping you get the services you want*):

> Reviewing case managers. Interviewing for staff. Staff change with no consultation. Enquiries to Centre management. Staff training - what training do they need to help us further. Staff changes in day Centres. Staff leaving. What is an advocate. About social workers. I talk about rude staff.

Rights and Protest

Came out in just under half of the responses (44%), often expressed in personal ways. Groups may provide forums for members to collectively confront rights and citizenship issues, which are often lost in the discourse of professionalism and social policy (Oliver and Zarb 1989). The first part of this process appears to be associated with becoming aware of one's rights:

> Finding out / standing up for your rights. Access to buildings for disabled people. Rights and responsibilities. Freedom and choices. Laws about rights. Votes, jury service. You and your rights. Things we are not allowed to do. Moving into the community. Rights, independence in all areas of people's lives. The unfairness of having

> to pay to come to our day Centre. Choices. People's rights about not smoking. Ken Simons came into tell us about making a complaint. Videos about disability. The changing policy which was brought into our county last year.

General government policy received a similar amount of attention and the importance of advisor support in illuminating policy guidelines was emphasised:

> Policy. Disability issues. Advisor spends a lot of time helping people understand issues such as civil rights bill, community care act, etc. Education, politics and child care. Lack of visibility of women in politics. Civil Rights. Community issues. Access matters. Civil rights bill. Rights, power and independence. Local issues for people with learning disabilities (sic). Community care assessments and charging. Local government reorganisation. County plans.

Finally, awareness can breed protest on a general and personal level:

> Stick up for your rights. National protests. Write to the Prime Minister. Protests against day charges. Letters to the Borough engineers [re: road safety]. Letters to fellow service users complaining about rubbish. Write letters to people about lack of services for people with learning difficulties. Opposition to day Centre closure. Spoke at local council chambers about day charges. Meeting with the local MP. Disability workshops and seminars. Disability awareness. Workshops to tackle councils about dog's mess. Took action about the death in a fire of one of the residents in a house where there were several residents. Ideas how to get Elizabeth's clothes back from the laundry - someone in the group sent her clothes to the laundry and they were lost. We are working on how to make sure they are replaced by the convent.

Services

Are talked about (30% explicit reference), and evaluated:

> Social services plans / policies. Activities of other organisations
> such as social services. Who should get services. Social services.
> Problems with the health authority. Transport. Bus passes. We talk
> about what happens at our local services. Service provision. Local
> gateway clubs. Further education for people with learning
> difficulties. Transport policy.

Links between services (or lack of) were observed ('going to dancing on
minibus is very unpopular - we value our independence and wish to go on
public transport'), while some responses indicate that groups and individual
members are involved in consultation with services-providers:

> Social services consultation meetings. Representatives on planning
> teams / running user-led forums. Consultation work with social
> services. Setting code of conduct for all service users including staff.
> we have helped with a health leaflet to advertise the community
> team. self-advocate involvement with Centre brochure. sending
> representatives to talk in college. Trained sub-group to decide who
> gives training. Projects to enhance tenants activities. Helped with
> leaflet to advertise the community team. Consultation. Monitoring
> and evaluating the five year plan passed by local social services.
> Consultation. MENCAP - our views on what they should be doing.
> We talk about how to get the best facilities.

Homes

As community care resettlement policies are translated into action, self-
advocates consider the affects upon their lives (27%):

> Resettling back into the community after living in a large 'mental'
> hospital. Independent living. Moving people in and out of hospital.

> Local institution closing. housing and staff support. Group homes. Living on your own. Hospital resettlement. The move - our house is being pulled down. Living with other people. Moving into the community. Group homes. Community living. Where people live.

Members have ambitions about community care:

> People want to have their own flat. We are organising a conference on moving into your own home. Resident rights. People having a choice about moving to a new home. Closure of hospitals and shortage of money to put into the houses of the people being moved into the community.

The affects of community care are also felt, reflected upon and evaluated by people with learning difficulties, as well as policy makers, parents and professionals (Means and Smith 1994).

Employment

Real work opportunities are of significance (27%). Work, or lack of it, got a fair mention. Also employment in self-advocacy groups was pointed to. 'Paid self-advocates' is another twist to the developing movement:

> Wages. Work experience. Benefits. Treatment by other workers. Day-time occupation. Work and support. Talk about work. Office work. Employment problems. Organising a petition about wages. Jobs and pay. Fair pay for students on work placements. Pay - not having enough. We want proper jobs with good wages and proper equipment. Interview techniques to get jobs. People getting work. Employing staff people with and without learning difficulties to support our group. Paying self-advocates.

Funding the group

Discussed by 17% of the groups:

> How to get money to keep going training. Funding (or lack of it) AD INFINITUM. Raising money for our group. Money - getting it and spending it. We discussed raising money for a conference and approached various bodies by means of a jointly written letter. Collecting money for people who need help more than us.

Members and advisors appear to be motivated in running their groups even when funding opportunities are limited.

(3) Typology of self-advocacy groups in the 1990s

The descriptive findings presented above reflect a self-advocacy movement that has developed markedly since the early 1970s. In trying to make sense of the findings, the typology of groups developed by *People First of Washington* (1984), previously introduced in chapter 2, will be re-visited in light of the findings from the survey. Three 'types' are examined: autonomous, service-based and divisional / coalition.

(1) The 'ideal' autonomous self-advocacy group

People First of Washington State (cited in Crawley 1990) define the *autonomous group* as retaining 'complete financial and organisational autonomy from any parent or professional advocacy organisation as well as from the service delivery systems'. Crawley (1990, pp98-99) continues:

'This type of group avoids any conflict of interests. Its members and their advisors can feel comfortable in taking any position without fear of recrimination. It is also seen as being independent and self-reliant from the outset'.

To identify these 'ideal' groups required setting criteria. Following Hanna (1978), Worrel (1987, 1988) and Shoultz (1997a), a group could potentially fit the autonomous model when it fitted three criteria:

Criterion 1 : Supporters are independent, either:

- *Voluntary independent(s),*

- *Paid (by group) independent(s).*

Only 23 of the 134 (17%) groups have only these supporters.

Criterion 2 : Independent settings for meetings where groups are not attached to services (Simons 1992, p6) including:

- *The group's own office,*

- *A room away from the Centre (and other services).*

15 of the 23 meet in these places, two meet in homes, one in a charity office, another in an independent organisation and, perhaps most surprisingly, four in Centres. Most groups (15/23), get together monthly, four fortnightly.

Criterion 3 : Financial and organisational autonomy (Crawley 1990, Sutcliffe and Simons 1993) were examined with reference to *funding sources.* The 15 groups who fit criteria 1 and 2, explicitly report the following funding details:

- 10 of the 15 (66%) *local authority* support,

- 4 (27%) *health authority* money,

- 6 (40%) said they receive *charity* money,

- 7 (47%) saw themselves as *self-funded.*

- Asked about other funding, two said they were financially supported by policy initiatives, two 'many', and the fund-raising, firm handouts and charities responses were each cited by one group.

These numerous funding sources suggest that the 'ideal' state of non-accountability to professional, parent and service delivery systems (Shoultz 1997b) is beyond many groups. Nevertheless, those groups who receive no indirect funding for their advisors (because they are voluntary or the group pays for their support themselves out of existing funds), were deemed to fit the third *financially autonomous* criterion (see table 5 above for details), thus emphasising their independence from service providers (Simons 1992, p9).

Placing all three criteria together, the following can be concluded from the respondents who gave sufficient information:

> Only 11% (15) of the 134 groups are strictly *autonomous* in that -
> supporters are only voluntary or paid by the group and independent;
> meetings take place in own offices or in rooms away from services;
> support is not directly funded by local or health authorities or bodies
> which have parent, professional or advocacy affiliation, therefore
> boasting financial autonomy.

From this analysis it would appear that *People First of Washington's* 'ideal' self-advocacy has become lost in the UK. However, a number of

characteristics emerge in the data set that are not encompassed in the 'ideal' group type detected by the criteria used above:

- Voluntary staff supporting groups in meetings away from services (5 groups) - e.g. a care assistant from a local hostel for people with learning difficulties supports a group on Wednesday evenings at the Dog and Partridge Pub.

- Those who have voluntary independents / paid by group independents and others as well (9 other groups in addition to 23 cited above) - e.g. A group is supported by an advocacy worker but also has their own support worker that they pay out of their funds.

- Meetings of *People First* groups taking place in Centres (14 groups) - e.g. A *People First* group hires the canteen of the local day Centre.

The rigidity of criteria in identifying the 'ideal group' may ignore many other set-ups that hold autonomy at the centre of their aims but who have seemingly non-autonomous structural elements. Furthermore, just because a group fits all the autonomous criteria may not causally relate to the promotion of 'ideal' self-advocacy.

(2)The 'conflict of interests' service system self-advocacy group

Some observers cite the *service system model* as the most widely adopted model in this country (Crawley 1982, 1988, 1990, McKenna 1986, Simons 1992). Crawley (1990, p99) explains:

'In this model the self-advocacy group is located in the service system itself. A meeting place is provided, there is no need to transport people to the meeting, and other resources are usually provided. However, conflict of interests can be a serious problem if the group takes any position which is viewed as unfavourable by the service itself'.

This type is usually associated with working groups or attention committees in Centres, hospitals, hostels and therapeutic villages (Simons 1992) identifiable by the combination of the following criteria:

Criterion 1 : Advisors are only:

- *Paid staff,*
- *Voluntary staff,*
- *or both.*

49 respondents (37%) cited having only this support.

Criterion 2 : Service-based groups meet in service-based set-ups:

- *Centre (ATCs, SECs),*
- *Hostel / home,*
- *Village.*

Of the 49, 29 meet in Centres and two in homes, although a high number meet outside of the Centre - 13). In contrast to the 'ideal' type, groups supported by staff meet more often - $23/46$ respondents getting together weekly, 12 monthly, 8 fortnightly.

Criterion 3 : A mixed picture emerges with respect to funding. Of the 31 groups fitting both criteria, with staff support and a service-base for

meetings (of which two failed to give sufficient information about funding), their details were:

- 16 of the 29 (55%) <u>explicitly</u> cited *local authority* support,

- 2 (7%) *health authority,*

- 4 (14%) said they receive *charity* money,

- 7 (24%) saw themselves as *self-funded.*

- Four report service sponsorship, along with fund-raising, carers input and 'many'.

In terms of financial or organisation dependency, those groups who receive funding indirectly from local / health authorities and social services (when their advisors are staff members and support is offered as part of the job), were deemed to fit the third criterion of *financial dependency on service-systems* (see table 5 above for details). Placing all three criteria together, the following can be concluded from the respondents who gave sufficient information:

> Only 21% (28) groups are *service-system based* - when their supporters are only paid staff supporters; meetings take place in service-based institutions (hostels, ATCs, SECs, villages); and support is directly funded by local or health authorities therefore leading to financial dependency.

So do these findings contest Crawley's (1990) assertion that service-system based groups are one of the fastest growing types in the movement? There are a number of problems with the criteria used above in finding the 'service-based' type. Many groups reject the imposition of crude categories, examples being:

- Those groups (13) with only staff advisors meeting together in rooms away from Centres - e.g. three care assistants from a local ATC support a group in a conservative club.

- Groups who have voluntary / paid independents, paid by group independents, as well as staff supporters (5 other groups in addition to 49 'just staff' cited above) - e.g. A group is supported at the day Centre by a member of staff and a volunteer.

- Those groups which are not the traditional trainee committees in service bases (as focused on by Crawley), but adopt other models with service bases. Simons (1992, p6) cites the small-scale study by Fiona Wright of *Yeovil People First* in 1991. She found that none of the local service-based groups were organised along trainee committee lines. Some were simply open to any Centre-user in the locality.

As with the 'autonomous' type the service-based model boasts sub-types within it. For example, as early as 1986, Cooper and Hersov had identified another, although rare, self-advocacy group in adult education establishments (Cooper and Hersov 1986). Again, respondents reject being placed to types.

(3 and 4) The divisional and coalition models of self-advocacy

Following Crawley (1988, 1990), two other distinct types have been recognised:

> *Divisional* - formed as a sub-section of an existing organisation for professionals (e.g. advocacy organisations, citizen advocacy schemes), parents or carers (e.g. MENCAP), these groups provide

immediate access to a variety of resources. However, there may be a conflict of interests between self-advocacy groups and parents, professionals and carers.

Coalition - composed of members from independent organisations who work together for the rights of disabled people (e.g. Independent Living Schemes, Mental health and disability initiatives, Organisations of disabled people). Individuals with physical impairments, mental health problems and learning difficulties come together as a larger group. While political power and ability to generate funding are heightened, people with learning difficulties run the risk of being over-powered by more articulate members.

On examining the findings it was impossible to distinguish between these two types. First, groups' specific independent allegiances were unclear. Often they received mixed support from citizen advocacy, professional advocacy, input from organisations *of* disabled people and parental, carer advocacy. Second, the specific status of advisors with respect to each type was unclear - both types could be supported by 'paid independent' supporters without service-system links. Who they were, or where they were actually from, it was impossible to say. Finally, the fact that few people with learning difficulties become involved in coalitions of disabled people (as reported by Simons 1992, pp6-7, and in my own personal communication with *People First London* members), may explain the under-representation of self-advocacy groups in the coalition category. By contrast people with learning difficulties are likely to have contact with citizen advocacy schemes (Flynn and Ward 1991, Tyne 1994), which may later bring alliances with organisations *of* disabled people.

The murky data defied the application of the two types. A combined working definition was required:

Divisional / coalition - formed as a subsection of existing organisations of disabled people, carers, parents, professionals and advocates. Independent to traditional service providers, these groups are supported by independent advisors, accountable to the larger organisation. Political power and ability to generate funding are increased, although, self-advocates concerns may be lost in the wider aims of the organisation.

Three criteria employed were used to identify these groups:

Criterion 1 : advisors are:

- *Paid independent supporter(s) / advisor(s)*

36 of the 134 groups have only these advisors. Those that gave more detailed descriptions put either 'advocates' (24), 'co-ordinators' (4) or 'independents' (3).

Criterion 2 : meeting place, picked out groups that get together in:

- *Independent organisations,*
- *Initiatives,*
- *Charities.*

17 of the 36 meet in these places, others in Centres (3), rooms away (8), own offices (3) and in hostels (2). Of the 35 respondents, 8 get together weekly, 10 monthly and 12 fortnightly.

<u>Criterion 3</u> : Now to funding:

- 3 out of the 14 who responded (21%) <u>explicitly</u> cited *local authority* support,

- 4 of 15 (27%) *health authority,*

- 6 of 13 (46%) said they receive *charity* money,

- 3 of 14 (21%) saw themselves as *self-funded.*

- Service sponsorship was reported (4 groups), along with fund-raising, firm handouts, charity and policy initiatives.

Numerous funding sources are received by divisional and coalition groups. Specifically, to find the 'pure' types, those groups who received funding indirectly from various independent organisations for their advisors were deemed to fit this third criterion of *financial dependency on divisional / coalition organisations.* Cross-tabulating the three criteria, the following can be concluded from the respondents who gave sufficient information:

Only 13% (17) groups are *divisional / coalition* - their supporters are only paid independents; they meet in the premises of independent organisations; support is indirectly funded by independent, professional, parental and advocacy affiliation, thus boasting divisional or coalition status.

As with the other categories, many collectives fail to be represented under the label of divisional or coalition, even when they would perhaps align themselves with such a model:

- Of the 20 groups that meet in independent organisations, two are supported by paid staff - e.g. a social worker supports a group which

meets every Wednesday night in office space rented off the citizen advocacy organisation.

- Those groups who have paid staff, paid by group supporters, voluntary independents as well as paid independents (9) - e.g. a group employs two of their own support workers and, in addition, pays for a co-ordinator from the local Independent Living scheme to help train the supporters.

- Independent groups meeting in 'dependent' places, three groups who have paid, independent support get-together in Centres. In contrast what about those groups who have their own offices but are supported by advocates - are they less or more divisional than other groups?

Appraising types of self-advocacy - so many groups, so few categories

It would appear that the typology literature has dated as the movement has matured. Only 60 of the 134 groups (48%) are accounted for by the typology. 74 defy classification, like the one below:

Group 'X' - are supported by Tim, an advocacy worker from the local Independent Living Centre. He sees the group every Thursday lunch in his dinner hour. Meetings take place in a room in the Centre although members flock in from work, Centres and homes. It's called the 'Talk Our' group and anyone with learning difficulties is welcome. The Centre manager gave the group £400. This pays for coffee and the rent of the room for four years. Tim was chosen out of a number of prospective supporters by the members.

The responses obtained in this postal survey resisted being slotted into categories. The organisational, financial and structural components of groups made 'pigeon-holing' difficult perhaps impossible. Group X, above, defies being labelled. To classify loses the richness of the structure. A typology may provide a useful starting point, but the strengths in a typology's simplicity are also its weaknesses. When a group is identified as 'service-system' based (as 21% of the group were) there are problems in applying the assumptions that are tied to that category. Downgrading a group because of its purported stifling structure supposes that services have no worth at all (McKenna 1986) and pitches understandings at a surface level. Consequently, the political ambitions, aims and actions of supporters and, more importantly, self-advocates, go unrecognised, hidden behind a negative label.

Reflecting on the survey findings

The survey findings are useful. They capture a snapshot of the movement at large. They reflect some of the diversity, developments and variety in what some have described as the last civil rights movement (Shakespeare 1993a, Campbell and Oliver 1996, Bersani 1996). Some of the concerns of self-advocates are highlighted, from plans to get married, living independently, wanting a job through to political protests. Moreover, the dilemmas of support are illustrated in the many roles and statuses held by advisors. Self-advocacy has come far and now is the time to take stock (Shoultz 1997a, 1997b). The aim of this thesis is to appraise self-advocacy in the lives of people with learning difficulties. This aim is only partially achieved by the survey. The personal impact of being in a self-advocacy group and the

actual workings of self-advocacy groups remain are not illuminated by its findings.

The movement's insiders who responded to the survey were lost in the search for an overview. When groups are penned into a structural typology members' actions are hidden by the specifications of that model. In the literature these types are not described as neutral concepts. If a group is service based it is limited, if it is autonomous it has great potential (see for example Crawley 1990). If an advisor is a staff member they are in an impossible position (Hanna 1978), if they are independent of professional status they can properly facilitate self-advocacy (Worrel 1987, 1988). Although structural constraints upon empowerment are undoubtedly important (Tomlinson 1995), it should be remembered that the actions of people with learning difficulties in the disabling environments of the 1970s, gave rise to the birth of the self-advocacy movement in the first place. The survey findings and previous literature run the risk of ignoring everyday self-empowering acts of people with learning difficulties.

Conclusion

This chapter has described and appraised the findings from 134 self-advocacy groups in the UK. First, responses to each survey item were summarised, highlighting the complexity of group structure, membership and support. Second, the group discussion topics were thematically analysed, indicating the multitude of issues that concern self-advocates. Third, responses from the 134 groups were analysed to see if they fitted the typology identified in the literature. It would appear that the typology has dated as the movement has developed. While limited in the extent to which

it delves into the movement, the postal survey sets the scene for subsequent empirical work in this thesis. This chapter has described the heterogeneity within the movement but falls short in explaining what this means for people with learning difficulties. Consequently, a number of general questions emerge from the survey findings. First, what do individual self-advocates get out of being in self-advocacy groups? Second, how are self-advocacy groups organised in practice? Sections 3 and 4 attempt to answer these questions.

Section 3

Living Self-advocacy: Stories of Self-advocates

Chapter 6

Five Life stories of 'top self-advocates'

Introduction

This chapter presents the life stories of five top self-advocates. Four of the stories are collaborative efforts between me and their narrators. Joyce Kershaw wrote her own story, which is presented in this chapter, while our collaborative effort is presented in *Appendix 3, 5*.

Jackie Downer - 'Ask self-advocates'

Jackie is 30 years old and is an experienced and well known self-advocate. She has worked as a self-advocacy development worker since 1990 and is involved with many organisations, workshops, research projects and service users' forums. She is a central figure in the Black People First movement. At the time of being interviewed she lived with her mother near to her office but was looking around for her own place. Jackie sees self-advocates as diverse and has encouraged others to value the differences amongst people. Self-advocacy can mean different things to different people. For her it is linked to her experiences as a black woman. This is Jackie's story:

From school to the library

I was in special schools up to the age of 16. Funny buildings, you were *labelled* as soon as you got there. You should have a choice, you should be able to go to normal schools with support. I didn't then. No motivation, no exams, put you down, embarrassed, no positive things about it. Afterwards I went to college and was there for five years. That made you grow up, a 'slap in the face', no one tells you about the stresses you have when you leave school. You feel isolated and you get depressed but at least you're not going mad watching TV 24 hours a day. God bless college. I changed colleges because I couldn't get a job, not even basic stuff like shop assistants, rejection upon rejection. It starts to make you feel small. I stayed at home and was depressed for a year. I wanted a job. I thought about myself as a black woman with learning difficulties. People look at your disability and not you as a person - that's a common experience. I didn't

like the term mental handicap and still don't. A lot of people still use the term but I lot don't like it. It's like the word 'nigger', it puts up a barrier against you. The term mental handicap is still used in a lot of policy and lots of professionals still use it. People want to keep it in policy because it gets them money. It says these people are poor. Like MENCAP they used to use 'mental handicap' - we used to call them 'MENCRAP'. I'm not mental I've got a disability - that's more dignified. We've all got some kind of handicap and we all need some support especially when we get old. I prefer learning difficulties and learning disabilities. I'd chose both, they're as positive as one another. Its up to the person, it's up to the individual. Some people might not like to be called or labelled anything - I'm just me. You should ask the person.

Mum was strong. She was very protective because I wasn't like my brothers and sisters. She wanted to protect me more and it was hard for her to let go. Parents are very scared to let go of their children. Some parents *want to* but don't know how to - always looking at disability. Parents say, 'I want my child to die before I die'. They still have a hold on to you even in adolescence. My Mum found relationships hard. Parents think they don't know about sex - they find it hard to talk about things. It's harder even now because I'm grown up and I need a life. I sat down and talked with my Mum. I told her 'there's things I've got to do, I'm one of the lucky one's, others have more severe learning difficulties'. 'I'm 30 ', I told her. She's gotta let me go and she found it hard. Some parents won't want their kids to do things and they need to have their own support group.

Eventually I got job in a library - It gave me confidence. Right place, right time. I was involved in a training programme, different organisations

provided different jobs. I chose the library because it was an easy option - I couldn't handle working with kids, or parks in the winter. I was there for six years, bored after three.

Becoming involved in self-advocacy

I had no real involvement with self-advocacy. I used to help support other people with learning difficulties in evening classes as a volunteer. In 1990 I heard about the job I have now - 'self-advocacy development worker'. Advertised all over the place, it said that a person with learning difficulties was wanted rather than a professional. It said that the person would be looking at services for people with learning difficulties and supporting their choices and say in the services. I was desperate for the job. A teacher helped me fill in the application forms and I handed them in personally! I thought, 'I won't get the job'. The interview was two weeks later, I got there one hour early. When it was my turn I went in and five people were waiting. I was scared, some of the questions they asked I didn't know, and I told them 'I'm nervous'. They got back in touch with me two days later and told me I got the job. It brought tears to my eyes, it meant so much to get that job I was over the moon. Mum wasn't bothered, just pleased for me. People show love in different ways. She never cuddled me. She said, 'That's fine'.

Since then I've learnt a lot from so many people and done things I'd never dreamed of doing. I went to the 1993 International *People First* conference in Canada. It's beautiful and clean. It was a celebration for people with learning difficulties to get together. A really nice experience, people uniting from all different countries in the world. In July 1994 I went to Jamaica *and*

India. The India conference, involving MENCAP and others, looked at services for people with learning difficulties over there. There are very little and the ones they have are inadequate. I worked with the Norah Fry Centre looking at services for black and ethnic minorities. We had a conference and a book came out but other people are getting the credit for it. I speak to professionals and some professionals are... professionals. Others are ace - they know where users are coming from. Some service managers are good, some bad. Some listen, some don't. We usually target ones that listen and want to change things. Some speak jargon, don't know how to speak to people with learning disability because they're doing paper work. We only see them when there's problems.

In my job I talk with people with learning difficulties about many things. Things they like about themselves, how they feel about each other and about coming to the group. Campaigning, training, conferences about themselves. We have workshops on leaving college, getting a job, being independent, relationships, parents, when to say yes and no. We set up parties, events, we go to pubs together and the church. And we produce a newsletter. People have changed so much. I would have done the job in my own time. It's great to work with people you know. You know where they're coming from. They give me strength to do that. You might get it wrong but you can try.

What self-advocacy means

People with learning difficulties sometimes don't know what self-advocacy means. Broken down it means, 'Speaking for yourself', 'Communicating in other ways', but It's *personal*. For me it means that I can speak for myself.

It means I've got a voice and even without a voice I can communicate in other ways. It means yes and no - most important - 'No, I don't want tea, I want coffee, I didn't want sugar' - all the things we take for granted. It means people must listen to me, I can take a risk, I can have a relationship, that can be hard. I can think for myself, I can go to the shop with support and if I need help, people can help me. I can cry if I want to cry. Take responsibility and make myself responsible. It means other things to other people. Linking it to myself as a woman, as a black person. Sometimes that can be hard if you've always been down, had negative vibes, that's important. My mother gave me strength to cope with life. My mum is a single black woman - she gives me strength. The Lord as well gave me strength. I believe in the Lord. Faith has helped - I'd be crazy by now, I can believe in myself only so much. Lord gives me strength. And friends are important to me as well. When you leave college you get cut off from friends, then what happens? Coping with bereavement, when you talk to someone about your feelings - that's part of self-advocacy.

Self-advocacy is a network of people supporting one another. You need a support network - am I doing my job in the right way? I need help. Everybody, even if you haven't got disabilities, needs support. What would I say to others who want to get into self-advocacy? I would say - this group is going. How do you feel? As people with learning difficulties, we're campaigning and this is great just for you to relax and say what you wanna say. We're not forcing you to come - but you can come if you want - talk about things from heavy to light things. You don't need to go over the top organising pictures, theatres, parties, meeting with other groups or self-help groups. Basic stuff first and campaigning later *but* you don't have to. You can just chat - you don't get the chance in the Centre or at home. *People*

First is both self-help and politics at the end of the day - it's up to the person to decide. If I make a mistake, then support me. No wrongs or rights.

How to support self-advocacy groups

As a worker I know I have power to tell people with learning difficulties what to do. I can use it and abuse it. How I see my power as advisor, I need to look at. Workers can spoil members by being too caring. That's dangerous, they relax. Be careful about caring. Paid workers create problems. I've got more power, I know that, and I've got to be careful. I'm their own worst enemy sometimes, pushing too much and people need to go at their own pace. Advisors need to explain to groups - break it down and ask. The ideal advisor is someone who supports the group, keeps their mouth shut, encourages the group to do what they want to do, be independent. They're there to support, write down for people who can't, advise a little bit, sometimes don't advise. Try to work together to give help when self-advocates need help. I would prefer outside advocacy supporters because they have no involvement with services. The more independent you are the more free you are, but it really depends on the advisor. There are good supporters, good advisors but it needs to get better.

On the self-advocacy movement

Self-advocacy is the in-thing now. If you're not speaking to users you're having problems. The movement is going from strength to strength and things are gradually happening but taking time. It's happening more in some places than others. The picture is good. Users are challenging, with support. Years ago policy makers, managers did it, now they're scared.

Users are getting more and more involved in different kinds of ways but cuts in education and support for groups will affect people with learning disability. People with mental health problems, children, people with physical disability get more support. People with learning disability get some support but not the same.

Everyone from the health minister to professionals goes to certain groups but they need to network with other *People First* organisations. Certain groups get mega bucks but they need to delegate to others. It's unfair if other groups want to have, say, a mini-conference and the chance to talk about things. With some groups everything is me, me, me - they think they can do everything. They need to network, need to share work. One or two groups can't do everything, if you think this you are treading on dangerous ground. What do I think of England *People First*? Who's England *People First*? Who are they? Who's in control? At the start I didn't know but now they're trying to get people with learning difficulties in control. Supposed to be people with learning disability. People with learning difficulties are in control when they delegate work amongst themselves. If one group does it, they're not uniting together, no network. There's always one *People First* group, one organisation, taking the power - we need to share things out. Black *People First*? If you see one you tell me - no such thing. It was gonna exist but it doesn't. People need space and choice - black, gay men and women, children. I set up a black friendly group and it was stressful. People were saying 'Why can't we have mixed groups, what's wrong with us?' You can segregate yourself, people need to unite and segregating doesn't help the movement.

Post-script - words of advice

At the end of the day you've got to be yourself in the so-called movement. This is my experience. Every experience is totally different. and you need to go back and ask other self-advocates. I like others to tell me if what I'm saying is okay. You can't just go by my experiences, I've not got all the answers. Instead of reading about it, ask other self-advocates.

Lloyd Page - 'Go for it'

Lloyd is 36 years old and is a long-time member of the self-advocacy organisation People First. He has been involved in projects for University courses, consultation with various committees and the production of many reports. His involvement with People First began in 1984 and he hasn't looked back since. Lloyd argues that self-advocates are 'adaptable', as shown by his People First group where many opportunities are available to learn new skills. I first met Lloyd at his group's office. He was photocopying a report, that he had co-written, evaluating local hospitals. He was keen to explain the many projects that he and his colleagues were doing and made me feel very much at ease. This is Lloyd's story:

From the Centre to People First

I was in Day Centres for 17 years. In those places I didn't do a single thing. Everybody kept sitting around doing nothing, just sat on their backsides - *doing nothing* - like I was doing. We used to get 75 pence for a day's work in the Centre - that's a pittance. You could say that things changed for the better about ten years ago, when I heard about *People First* from a couple of social workers at my Centre. In 1984 I went to the first international *People First* conference which was held at St. Mary's College in Twickenham. When I went to the conference it was hellish! I gave a speech to over 300 people - it was nerve-wracking. In the early days, self-advocacy and *People First* grew mostly in America, starting off in Washington DC and in '84 self-advocates came to England from different parts of America.

At the conference the England people said that they wanted to start up a *People First* group, so we all said, 'Why not'.

I came back from the conference and helped set up a group. At the time our group was called *People First* and now there is another group which is a spin-off. There were over twenty people in the group at the start and I was link person there. I was also secretary for quite a while. At the start we'd meet in peoples' houses but now the group meets in a community hall that's let out once a fortnight - it's a regular thing. We would talk about transport, Day Centres, holidays and because we were losing our four pounds pocket money - the *pittance* that we used to get from the Centre. Right from the start people were very chatty because they'd been given the chance to speak.

Around that time I also got information back from Twickenham. I had letters from all the other groups so I wrote to them. They told me that the next international conference was going to be in Canada. To get me over to Canada my mother and about four of her friends fund-raised for four years. They got £4,300 and that meant we could send four self-advocates and one supporter to Canada. When you're at these conferences you go and visit places and you go and have chats. I gave a speech and I also remember singing on the Karaoke over there - this was videotaped by somebody but I haven't heard from them yet. I met lots of people, quite a load, some who I have kept in touch with. One person I met was Pat Worth - it was great because you listen to his life story and it's brilliant. I got involved with my present group ten years ago. I went down to their offices and I asked if there was any work and they said, 'Yeah, there's plenty of work for you to do'.

Why self-advocacy?

Why did I want to get into self-advocacy? Because it's a good thing to do - speaking up for yourself. Being in a group helps you to speak out. By speaking to people in the group it gives you the confidence to speak to other people. Sharing ideas you can get more out. Self-advocacy means that people with learning difficulties have a right to speak up for themselves. To see how they can express themselves in ways that people, members of the general public, can understand. Then you can start to think about what you're going to do and what you're going to say. At first it's difficult, it took me a long time but you need to gain confidence for yourself. You also need to believe in yourself, what you're saying and what you need to do. I didn't get the chance to do it before I joined *People First* - not a chance because I was stopped from speaking out. There wasn't anybody to listen to you and when I did speak out I was shouted down. Other reasons why I wasn't give a chance to speak out? Lack of community I think - lack of community, like neighbours. I'm quite lucky - I've got lovely neighbours, I feel that I've been more accepted into the community now more than I would ever be. That's not just because of the way I am. Right from the beginning Mum said that I had a place in this world and I have got a place. My mum and I, we went for it, we said that people outside had to learn about people like me. That I wasn't daft, I wasn't a danger, I am a human being - I'm just a normal person like all of them and I have a right to live in this community. Being in my church has also helped - the church accepted me. There was a bit of a debate going on if we wanted women priests or not - we voted against. I said, 'No women priests for us mate'. No way boy - no way hoosay!

Why learning difficulties?

I prefer the term learning difficulties - it's a better term. Why is it better? Because it's much nicer - we want to learn and *I like it*. I got the council to change the name. I told them that we weren't mentally handicapped, we were just ordinary people with learning difficulties, like members of the ordinary public. I also wrote to our labour councillor and I gave them some strong words - phwoar! The councillor said, 'All right Lloyd I'll put it to the council and I'll let you know in the next couple of days'. Well, he spoke to the council and he wrote back to me and I got the name changed. They didn't use mental handicap in Centres after that. The same thing happened with MENCAP. They didn't want the label of mental handicap changed because they thought it would interfere with their fund-raising. Now MENCAP have called themselves learning disability - I don't like that term. Some people still use the old terms as well but that happened more in the old days when institutions were beginning to close down. If you ask people who have the label of learning difficulties they prefer it - and that's what it's all about - this is what it's all about and here we are.

Lloyd the self-advocate

People First has been brilliant for me. Get up, get washed, dressed, listen to some music in the morning, go to work as normal - do what you gotta do and that's it. In our office jobs are shared out. Typical normal day? Phone rings, phone rings *again*, chat to people, look at what jobs need to be done, photocopying, write letters, send things out - I'm sort of one of the administrators. I get loads of phone calls from universities and people

enquiring about information. Once one project is finished another one arises. I take it in my stride.

I've worked with so many groups. Like the Central Council for Education Training and Social Work and I'm on the Equal Opportunities Committee. I'm working with the special investigations team up at MENCAP. They've asked me on board to do articles for their new magazine 'Viewpoint'. Also I've worked with the Open University on the *Equal People Course*. Let me tell you about it. This is from a leaflet about this course - 'It is for everybody, people with learning difficulties and carers. If you are interested in finding out more about learning difficulties then this is the course for you. You can work on your own, with a partner or in a group. It is written clearly and uses pictures, it uses videos and audio tapes - you don't have to read or write well to do the course'. Here's another bit about it, 'It shows people with learning difficulties as equal people' - we are equal people - 'It shows family and carers as people with needs, wants and lives outside their family. It shows the needs of paid staff and others who work with people with learning difficulties. It shows ways of working which give people with learning difficulties, staff and carers a better quality of life. It shows how people with learning difficulties, carers and staff are prevented from doing things and how they can change this. It shows how everybody can have more control and power over their lives. It shows how everybody can work together to plan and change things that affect their lives'. I'm going to do a five-minute stint about this course at a conference soon. I was on the course team and we put forward ideas - we just didn't want to be on the sidelines - another way of not being involved. I gave a presentation to the senior management team at MENCAP. MENCAP should use it - They need to

know a bit more about us as well - now they have accepted us as people with learning difficulties.

I'm also involved with a Day Centre for people with learning difficulties to get them to speak up for themselves - the users. I'm working on a hospital project and I've taken some photographs of all the hospitals that I visited. I give talks at Universities to doctors, nurses, professionals. I think that's important because professionals need to learn about us, they need to understand us. I must admit that I've got a bit of a negative view of doctors, nurses and professionals. You see, they don't listen to us. But they're beginning to listen - what do we need? I talk to students and do lots of workshops on self-advocacy.

I've also been to the Houses of Parliament when I fought for people with learning difficulties' civil rights. That was around the time when Nicholas Scott was Minister for Disabled - stupid man. I work for the Suzy Lamplugh trust at the home office, see, I'm also a government official as well you know! No wonder my bedroom is full up with papers! If that's not enough, I've also appeared on the television a couple of times. I did a video for the police and it was shown on TV. I was made out to be a psychopathic murderer called 'David Mackensie'. There was the detective there - he was quite a nice person actually. Anyway I had to pretend to be picked up on the street, taken into a police station and put in a cell. They filmed me through the cell - it was excellent. There was a serious side though to the film as it showed people with learning difficulties being charged with something that they hadn't done. And it explained that now, if people with a learning difficulty are taken in by the police, they must now have an appropriate adult with them. Also I have done a video for London Transport (another

Channel Four production). They came up to see me at the day Centre and they took me on the tube. They were filming how I'd react to tubes and to see how London transport was helping people with learning difficulties. I also helped with a thing on London transport for a magazine on accessible transport - that's how you can portray people with learning difficulties as they really are.

I've had an exciting life - I've enjoyed *People First* more than I did at the day Centre because you do things all the time. I've done lots of things - I suppose there's not many self-advocates who could say they've been on the television twice. How do people react? I should say, 'Aye, aye jealousy will get you nowhere'! No it sounds like I get a lot of flack - it's only good fun. I think other self-advocates look at me and say, 'Blimey, he's done well for himself'. Do I think they see me as some kind of role model? Sometimes, yeah, sometimes. If anybody asked me any questions about a project they'll go, 'Oh, I think Lloyd knows' - they come to me. Now my Auntie Joan she calls me a 'gopher' - 'go for this, go for that'! No, seriously, my friends and family think me working for *People First* is really good. They say, 'Blimey, where's he off to this time?' It's been really quite fruitful. My mum has never stopped me at all - it's great - she's encouraged me right from the very start, she's backed me one hundred percent and I'm really grateful for that. I've got wonderful friends and a lovely family. Has it given me a purpose? Freedom of life - it's great. You know I have made so many friends and I've seen them come and go. The best friends I ever got were the friends at the office. I've got to know so many people and I've got to know a lot more things than I would've known.

On the movement

I've seen *People First* grow in ten years that I've been there and I'm one of the original ones that started it. It's grown in good ways and I think it's grown for the better. I think self-advocates have got the power to do what they want to do. I don't think there's anything that can stop that power. Self-advocacy is looking good - more stronger. Now with England *People First* I don't know what to think about it. A good or bad thing? You've got to weigh up the balance between England *People First* and the other groups as well. There's a question of money and if it runs out it's a difficult question to answer. I would like to see England *People First* getting in contact with groups - getting groups together. Our group is a much better set-up in all the groups really and it's much more central than others as well. We have got five paid supporters and ten voluntary workers. The self-advocates don't get paid but are given their expenses back. I cannot be paid because I'm on benefits. We need supporters for everywhere we want to go and the money we charge for supporting groups and carrying out workshops goes to the office. This all helps us to keep going. At first I did think we should be paid but this is not possible. I am really pleased to be part of all this so don't mind for not getting paid. In ten years time I'd like to go onto much bigger things, do some more work for Universities and stuff like that.

Postscript - Words of advice

What would I say to other people with learning difficulties if they wanted to get involved with *People First*? One word for that, 'Go for it'. I'd say, 'Hey you, get out there and do your piece and I'm not gonna stop you'.

Joyce Kershaw - 'Raise your voice and not be frightened'

Joyce Kershaw is 65 years old and a founder member of her People First group. Her long-term involvement within the self-advocacy movement has led her to be widely recognised as something of an expert in the field. She was co-researcher and author of a groundbreaking study of services for people with learning difficulties by people with learning difficulties (Whittaker, Gardner and Kershaw 1993) and remains active within the movement. Outspoken and to the point, Joyce comes 'straight out' with her opinions. She asked me to write the following statement down:

'Danny wrote two stories. Joyce couldn't read the first and she didn't like the second one. Joyce kept pulling Danny up, so she wrote her own. You will see that I have been going over the things Danny missed. If there's anything that I have missed that I told Danny before he wrote his story, about the Centre and other things, well I'm 65 and I just kept forgetting bits. As you read my story you will see that I keep going back over the old days, when I kept remembering little things. So I would like you to read both stories (Danny's and mine) but I think you'll think mine is better'.

Joyce Kershaw, November 1996.

'My story' is presented in Appendix 3, 5, Joyce's story is presented below:

Life Story 2 - 'Joyce's story'

As far as I can remember, is when we came back to live on Northgate. I remember we used to have a grocery shop. I had to stop off school because of my fits. When the war came my brother Harry and my brother Dan were

called up like a lot of both men and women. When there was an air raid we used to go in my Grandma Marsden's cellar, till it was all over. I also had to stop having piano lessons. When I was 13 or 12, my mother got a telegram to say my brother Harry had been taken prisoner of war. A week before we got the news, a gypsy asked my Mam if she wanted to buy something from her and my Mam said, 'I'm sorry but I haven't got any money'. The gypsy said, 'That's not true, you have some small pence, but you need it'. Then she said, 'But you're worried about something but don't worry you're going to hear some good news'. That's when we heard about my brother. Soon after that a lady came to our house. She said I had to go to this school near Liverpool. I didn't want to go but they said I had to go for my education. When I got there it seemed strange being away from home. There were two nurses and a matron. When morning came around, the night nurse woke us up at 5.00. Then at 5.30 we had to get up, get a wash and get dressed. Then make our beds, then we had to go into the little dormitory and make one of the girls' beds, all before matron came down stairs at 6 o'clock. When we'd done that we had to dummy the dormitories, they were heavy too, then we had breakfast. The first week I was there, I didn't like the porridge, it was like sludge. Also I never used to like the marmalade but I soon got to like both of them when they wouldn't give you anything else. I soon got hungry and began to eat anything they gave me. We used to play monopoly, cards and pool, except for Wednesdays when we helped to bath the little ones. Then on Friday we used to sit round the fire and darn our stockings and if there was anything else to mend we mended them too. On Sunday we went to church. I used to be in the choir. At 14 I was confirmed.

I didn't have many visitors like the other girls had. Once every year we went home for two weeks then we had to go back. When I was 16 I left

school and I came home for good. My first job was at Woolworths. My Dad went with me and he explained to the manager that I had fits and he told her I hadn't had one for two years. The manager was a lady and she said, 'Yes, you have a job, I don't mind helping people with learning difficulties'. That's where I met my husband. He was a cook in the army. He was walking around Woolworths and he asked me if I would go to the pictures with him because he didn't know his way around. He was from Oldham. We went to the pictures that night and he asked me if he could see me again. I said yes. When he went back off leave I wrote him a letter every night. I also got a lot of letters. When he came out of the army, he got a job baking. Every weekend we used to go off on the tandem. When I was 18 I was married. My husband was 20. We had a little house up the Paddock. I had a little job in a fish and chips shop. My husband got a job as a bus conductor. Then he got a job as driver. We were married for seven years. Then he went off with my best friend. We had been friends since we were little.

When my husband left me, my mother and sister came up to see me and I went back home with them. I lived with my mother for a while. Then both my mother and myself went to live with my brother. We used to look after both my sister's two boys, the youngest was 2 the eldest was 10. We also looked after my brother's two boys, youngest 4, eldest 10. My sister died when she was 34. I stayed with my sister for two nights before she died, so my brother-in-law could get some sleep, so he could go to work. Both me and my mother used to keep the house clean. I used to help her with the washing. We used to wash my brother-in-law's shirts and his two boys, and my brother's things and his two boys. We didn't have a washing machine then. We used to do all the washing in a tub, scrubbing board, scrubbing

brush and ringing machine. My mother used to love baking and cooking. When she wasn't doing that she used to knit things for the boys. When she had done that she knitted me a bed jacket. She couldn't follow a pattern. She just made her own patterns up as she went along. I remember my Auntie saying to me, 'Your Mam was such a good cook, we used to go up when we knew she was making buns or cakes and ask if we could have some'. When it was Christmas my mother made some smashing cakes. We used to like scraping the dish afterwards. I used to love hearing my Mam talk about the old days when she was young. I could listen to them over and over again.

I went to hospital to have a cyst removed. When I came out my Mam was very poorly. My brother brought my Mam a bed downstairs. She wouldn't go in hospital. So three nurses used to come every day, but she wouldn't let them touch her. She used to say, 'I can do it for myself'. But after they had gone, I had to do it for her and make her bed. I used to sleep on a two-seated couch and I was up six or seven times a night. The nurses told me if I didn't stop and get some sleep I'd be gone before me mother. I used to weigh 10 stones and I went right down to 7 stones. After my Mam died I could hear her shouting me for a long time, because while I was looking after her she used to always be shouting, 'Joyce'. Even if I went into the kitchen or away, she'd shout my name over and over again. But before she died, she saw my eldest brother's boy get married and my Brother Harry's two boys and my sister's boys.

My Dad came and took me to my Aunt's because I wouldn't go out and I used to wear navy blue for a long time. My Auntie used to take me out with her. We went shopping for some new clothes. Also I had my hair cut and

permed for the first time. I used to go a lot to my Auntie's. She lived in Batley. My brother used to take me and bring me back. I used to stay either two weeks or sometimes a month. I went on holiday with my Aunties and Uncles to Blackpool.

My Dad used to come over to see me every two weeks. Once when he was going back home, his legs let him down and he was in hospital for a long time. The Doctors said he couldn't go back to living on his own. So my brother said, 'He won't have to, he can come home with me and I'll look after him'. So when he came out of hospital my Dad lived with us. My brother put him in bed in the other sitting room and he slept downstairs. My Dad had arthritis in his legs and in his hands. I had to put a cigarette in a holder that he had, then I would put it between his little finger and the other fingers. Gradually his hands got a lot better because he used to try and pick things up until his fingers straightened out a bit further.

Then I went to the S.E.C. The first day I got there I met Stuart. He lived with his Mam and Dad in Sheepbridge. He asked me if he could come to our house, so I asked my Dad. He said, 'Yes, if he wants to'. The next day I told him he could come. He got on with my Dad and brother. He used to come down every night then, except for Saturday and Sunday. Then I went up to his house for my tea. All his brothers were there with their wives and children. His mother used to go out helping an old lady because she wouldn't have anybody else. That was after she had retired. I often thought about my Mam telling me about how her mother used to take in washing to help with the house keeping and when she went to school everyone had to stand in line while the teachers inspected their nails and their shoes. If they hadn't cleaned them they sent them back home to do so. Also she said

children these days don't know when they're lucky. When there was a wedding or a party my mother used to give me sixpence and I went to see if there was any food left over. I used to come back with a big bag full of food. She also told me whenever she went out when she was a young lady she put on her best costume. When she came back home she went straight upstairs and changed into an old dress and put her pinafore on.

Stuart started going on holiday with my Aunties and myself. Then one day my Auntie said, 'Next year why don't you go on holiday with Stuart's mother, I bet she'd like that'. So when we got back home, we told Stuart's Mam what my Auntie had said. The first holiday we went on was to Belgium. Then Spain, we went there twice. Then we went to Germany and to Amsterdam. The last place we went to was Italy. Stuart's father was poorly. He went in hospital and had one of his legs amputated. They wanted to amputate both but they said it would kill him. So that meant if they removed his second leg he'd die and if they didn't he'd die. Sometimes you just don't know what to do for the best. So after that he died. Two years later we went on holiday. Then the last time Stuart's Mam asked me, 'Where do you want to go this year?' I said I wasn't bothered and told her to pick somewhere. She said, 'I'd like to go to Italy'. I said, 'Well, that's all right with me'. But before she could make reservations to go she died and I haven't been on holiday since.

I remember when Stuart came to see me after he had been to town. He used to bring me two or three packets of cigarettes and a bag of fruit or chocolates. His mother used to give him £10 or £20. She spoilt him. I told her she'd be sorry some day. When Stuart was fostered he didn't get £10 or £20 a day, he gets either £8 or £10 to last him all week. He couldn't

understand it at first. It took a while for him to realise that he couldn't have what his mother used to give him. Now, when he comes down to see me, I give him some cigarettes. His foster parents told me I hadn't to give him any. But I remember the days when I hadn't got a lot of money and he gave me cigarettes and other things. I don't forget things like that. My Dad used to pay for all my holidays that I went on with Stuart and his mother. One year, near Christmas time, my Dad was very poorly and everyday when I went to the Centre I used to call the doctor. All he gave me was a prescription. Then on the 20th December we broke up for 2 weeks. Then the next day on the 21st December, my brother came and woke me up at 3 o'clock in the morning. He said, 'Your Dad wants you'. So I got up and went downstairs. He was sat in his chair, he asked me to rub his legs, so I did, then he said, 'Help me up, I want to have a little walk'. I helped him. The second time he wanted to try and walk he had a stroke. I had to put him on the floor and lean him up against my armchair. Then I went upstairs to fetch my brother. He came down and we both helped him into his chair. We hadn't got a telephone then. So I went out in my nightie to the next door neighbours. When I couldn't wake them I went a bit further down and they were up, so I asked them if they could phone for a doctor because my Dad had a stroke. Then I went back. My brother had to go to work. When the doctor came at nine o'clock he said to me, 'Your Dad's a very poorly man'. I said, 'I've been telling you that all week'.

Then he got on his phone and called an ambulance. I went with him. I had to sign some papers. Then they called my brother to come and pick me up to take me home. When I got home, I asked my neighbour if I could phone the Centre. I remember they were painting and Mr Jones, the Centre manager, was there. I told him about my Dad and he came straight up and

sat with me. He made me a cup of tea and had one himself. When we had finished our tea, he told me to stop crying, to wash my face, and try and get some sleep. He said, 'You don't want your Dad to see you like that, it might upset him'. So I cried myself to sleep. Then at three in the afternoon my next door neighbour came and woke me up. He said the hospital was on the phone. When I answered it the nurse told me my Dad had just died. When my brother came home, I told him what had happened. So we both went to the hospital to see my Dad. They said he died of a heart attack. I kissed him. He always told us, whenever he died, he didn't want anybody crying over him. But when you've had a Dad as good as mine, I couldn't help it. I still miss my Mam and Dad after all these years. My Dad was all for *People First*. He believed that we had as much rights as anyone else. I used to go all over making speeches.

How *People First* got started. Mr Jones gave me a small pamphlet and I asked him what it was about and he said, 'Speaking up for yourself and being independent'. So I asked him if there was a *People First* around near us. He said, 'I don't think so'. So I said, 'Well, there soon will be'. I asked students if they would like to join. At first there was five, then there was fifteen, now we have over twenty.

When we first started out, one of the staff said, 'I'll give you a year' and we've been going now for ten years. I work in the cafe at the S.E.C. In the old days I was the only one in the cafe so they named it 'Joyce's cafe'. Since we opened it to the public, they call it 'Swallow Cafe'. After Christmas they are going to expand it. When I was 60 years old they asked me to stop on and run the cafe. But Lesley, who used to be my keyworker, she gets all the new ideas for the cafe. Lesley has always been good to me,

like Mr Jones in the old days. When I was depressed Lesley would say to me, 'Have you got any money?' I'd say, yes, and then she'd say, 'I'll take you shopping after dinner'. I remember she always used to say, 'I love spending other people's money'. I used to feel a lot better afterwards. When Lesley was my keyworker, if I was 15 minutes late she would phone to see if I was all right. Now she's not with us all the time, nobody cares like Lesley used to. But when she had a break for a drink of tea with her group in the cafe, she asked where I was. Then she went to the office to phone me up. But I was on my way. That's what Lesley's like. It's not just me, but everyone in her group. If they're late, she'll phone to see if they're all right. If Lesley had something to say she would say it, then we would be friends again. I like her because she says what she has to say to you. She doesn't talk behind your back like some do. I'd rather tell people what I think, then forget it.

My brother and I now live in a two-bedroom flat. It's nearer work. I went to ask if I could go to the hospital for an X-ray, on my feet and back. When the results came back, he told me that I had arthritis. Now I have to have a stick. My brother used to like under-water diving. But now he goes playing golf three times a week - sometimes more. He goes all over playing golf.

We look forward to the future in *People First*. I could have said a lot more things about when I was a little girl. Such as you don't see children playing hopscotch and skipping and rounders. There were lots of games we used to play when we were kids. Now the kids these days, only think of going dancing, pictures and sex - if you give them 5 or 10 pounds these days they luck at you daft. I used to go on to Molly Meals for halfpenny carrot. If we had sixpence we thought we was well off. All you hear about these days,

someone has been raped or murdered, not just by men and women. Children commit murder as well. You can't leave your door open these days like you could when I was a young girl. When people go to jail, instead of hard work they have pool tables and television, instead of working. They'd rather live off the dole. Most don't know what work is. I blame the government.

I started to tell you about *People First*, then, by accident, I went on talking about something else. In the old days we used to call the staff by their last names. Also two staff would stand and say which row could go for dinner. But they used to eat their dinner in a little room. So I asked the boss if I could have a word with him. He said, 'Yes, what's the matter?' So I said, 'Aren't we good enough to eat with?' and he said, 'Yes why?' I said, 'Well, it doesn't seem so - the staff eat in a little room of their own'. So he said he'd see what they'd say at the meeting. Then I asked him, 'Can we call the staff by the first name?' He said, 'Why don't you ask them?' So I did. Some said yes and some said no. Those who said no I said, 'Well call me Mrs Kershaw'. Well, after all, Mr Jones said *People First* was about sticking up for yourself and helping others stick up for themselves.

When I used to be talking to staff, one of the other staff would come and butt in. We just used to walk away. But if they were talking and you butted in, they'd say to us, 'It's bad manners to butt in when people's talking'. So one day I was talking to the staff, when one of the men staff started talking, and they both started talking, so I said to him that interrupted, 'I was talking to him, it's ignorant to interrupt'. I said, 'At least that's what you told me'.

People First started in 1986. I also made sure that they didn't pick on those who were too frightened to talk back. Also in *People First* we share one

another's troubles. People look up to us now and listen to us, where before they used to make us look small, and they never listened to what we had to say. Also we are people with learning difficulties, not what people used to call us. I won't say the word because we got rid of it in some places, but there's still some that use that name. Never mind - we'll win some day. Even if we aren't there, we're thinking about the future for those children who haven't been born yet. That's what we do, think of the future, more than these that build houses and shops. They don't think about those in wheelchairs, who would like to do their own shopping. I helped to start a lot of *People First* groups up. One of the groups has their meetings in a Centre. We have a room outside the Centre. Also they have the staff for their advisor and we don't. Some of the staff tell them what to do, practically run it for them. We've never done that, we don't let anybody join, only people with learning difficulties. It's our group and nobody tells us what to do and that's how it should be.

Some parents still treat their grown up sons and daughters as children. That's not right. My Mam and Dad never treated me like that and I'm a lot better for it. I loved to buy my brother grapes, oranges or plums. I like to buy him something for his birthday and Christmas. When I ask him what he would like he always says, 'I don't want anything save your money', but I always buy him something. The thing is I'm running out of things to buy him because he has everything. When I say, 'Do you want this or that?' he always says, 'I've got it'. It's easier to buy for a woman than it is for a man. I feel good when I'm helping people. It's not just my relatives. I like helping everybody.

I've just remembered something else about the Centre in the old days. The staff used to put a show on for us at Christmas. They used to throw custard pies at one another. One Christmas, Mr Jones and two other men staff took 'The Three Degrees' off. They got dressed up in long dresses and wigs. Then Lesley pretended to have an operation behind a screen. Then they carried her off in a coffin. Some of the students went home and told their Mams and Dads, or whomever they lived with, that Lesley had died. They wrote in to say how sorry they were about losing Lesley. They'd only just got to know she had died. The staff had a good laugh over it, and so did the parents when they got to know it was just a show. Then three of the men staff dressed up in Ballet clothes and while they were dancing, Mr Gaunt's skirt fell down. Every time he picked it up and put it back on, it just kept falling off again, so he gave it up as a bad job. On my way home I couldn't stop laughing on the bus. I haven't thought about that up until now. But the Christmas my Dad died, we put on a show for the staff, just for a change. They called the play 'The witch that nicked Christmas'. We played in on the day we broke up. That was the 20th December. Then on the 21st December my Dad died and I was the witch in the play. So that was Christmas. I never thought about it until I was writing my life story.

Every Friday we used to play games, not just any game. They used to play the games that were on television. Such as 'Play Your Cards Right', 'Mr and Mrs' and a lot of other games. Every time there was a new game on the TV we used to try out on Fridays. They used to be good at 'Name That Tune'. I won some medals for swimming. That last medal I won for 40 lengths none stop. I also got a gold medal for shot put, discus, archery and javelin. The only thing I didn't get was one for shooting. I'd love to go

abroad again. I've got my wish after all these years. I always wanted a till for my cafe but they used to say they were too much money.

I don't know. These days if you break into a £10 note, or a £20 note, it goes in no time. You sit down at the end of the day and wonder where it's all gone to. It used to go a lot further in the old days.

When I lived up Nethroyd Hill, every night when I came home, I used to help all the old ladies off the bus and across the road. I used to call them 'my little women'. Some of them were bigger than me. I remember once, I had both my arms in plaster and one of the little ladies came and brought me a lovely big bunch of flowers and a card. When I read the card it said, 'Get well soon, we all miss you'. I sat down and cried. Because I broke my arms, a nurse used to come in the morning and dress me. Then at night she used to come and get me ready for bed. Since then I've had someone to come and help me get in the bath. There's Margaret, Brenda and Moira. Peggy doesn't come any more. They are all nice. They think of other *People First*. I like them all, I wouldn't change them for anyone else. When I was asked if I wanted someone new I told them, 'No, I'll do without a bath first'. There was an old lady that used to live on Northgate. She used to sit on her front steps and smoke a clay pipe. Her name was Mrs Riley. She was a nice lady.

I know I keep going back to when I was a girl, and the old days, but things keep coming back to me. Like before the war my Mam and Dad bought me a big doll and pram for Christmas. When I was at the school near Liverpool, my Mam wrote and asked if she could give my dolls and my pram away to someone who couldn't afford to buy their little girl anything for Christmas.

So I wrote back and said, 'Yes, I'm too old for them now anyway'. When I came home from the Centre one day, my brother-in-law was just driving his car in my brother's garage, when he turned round and said, 'I've forgotten to give Harry this and he's working over'. So I said, 'I'll give it to him when he comes home'. Then, instead of turning left, I turned right and fell off a high wall. I don't remember hitting the ground. When I came round I was in hospital. I kept asking the nurses and doctors, as they walked past, if I could have my clothes. They kept on saying 'in a minute'. Then when my brother came up at teatime, I said, 'They won't give me my clothes' and he said, 'You banged your head and you hurt your fingers. They might want to keep you in over night'. I asked him where my clothes were. So I got dressed and went home. When I got home my Dad said, 'You're not going to work for two weeks'. But the next day I got up and went to the Centre. My Dad said, 'You must have a head made of iron'.

We opened the café to people outside. I look after the money. After Christmas there is going to be a change. It's going to be made bigger with a bigger counter. It's going to be really nice. It'll cost a lot of money. Me and my friends go into the bus station cafe for a drink. We pay in turns. The cafe students and staff are going out for our Christmas dinner. I'll have to have my hair permed before I go. I should have gone to the hospital but I forgot. My brother Harry is taking me up in the car, then he'll be playing golf. He's the best brother anyone could ask for.

Well I can't see into the future so I'll finish now. I will say one thing more, and that is, I don't go to church now, but that doesn't mean to say I don't believe in God, because I do. I can't go to sleep at night if I haven't said my prayers. That's one thing I never forget. I pray for everyone in the world,

not just for people I know. I know there will be a lot more to say as time goes by. I might write again soon, I'll keep a diary, then I won't forget next time. I'll end on the 14th November 1996.

Anya Souza - 'It's not Down's Syndrome it's Up Syndrome'

Anya used to work for a self-advocacy group. A couple of incidents led to her leaving and she now spends much of her time designing and making stained glass ornaments, mirrors and frames. She also supports and promotes respite care, and has spoken widely about the rights of people with Down's Syndrome. When we met she was 34 and lived in her spacious and artistically decorated flat. Anya sees self-advocacy as an individual as well as collective concern. Although she herself now has little to do with self-advocacy groups, she still encourages others with learning difficulties to check out what they can get from being involved. This is Anya's story:

The early days

I was born in Hampstead in 1962 and in those days it was Mongol. When my mum had me she was 44, which is quite old actually to have a baby. When the doctors had me in their hands to hand me over to my mother, she asked them, 'Is my daughter okay?' The Doctor said, 'No, she's not okay, she'll be mentally and physically handicapped for the rest of her life', basically. My mother couldn't make head nor tail of that initially. She was shocked. Then a nurse came up to my mother and said 'Mrs Souza your daughter will be fine, you'll get pleasure out of her'. So I did, I gave her pleasure. A few years later, around 87 - 88, we were on television with Esther Ranzen, and my mother told her what the doctor had said. I felt like saying, 'Can I speak now? You should see what I've got - I've got two arms and two legs, I'm not physically handicapped actually'. I could have said that but they didn't give me a space to speak. I felt a bit angry inside

myself. People were talking in the audience and all that and it came back to my mother again. When Esther said, 'Don't ever give up', I thought that's a bit silly, because you've got to give yourself a chance to move in life - not give up. A bit silly I think.

We're half-Indian from my father. He's Indian Catholic. My mother was Jewish, she came from Prague. She came here when she was 16 and couldn't speak a word of English. She married twice, before she met my Dad and had us. She came in March 1939 and the war started in September of that year. She was Jewish but she wasn't practising. The same with my Dad. His family are Catholic but he doesn't practice. My Dad is a well-known Indian artist. My sisters, Francesca and Karen, they were born before me, I was the last one. I had support from them when I was young.

I was at nursery school and after that I went to a special school just for one term. I didn't like it there anyway basically, neither did my mother. I was only about five and at one point this teacher made a stuffed fish out of paper and two brown rabbits. *She* made these things not *me*. She made them as decorations for the school. Now you weren't allowed to bring them home but I sneaked them in my bag and came home with them. I showed them to my mother and said, 'Well, I didn't do this mum, so why am I at school? I should be the one learning'. I mean why are schools here on earth? You've got to learn it for yourself, not the teacher - they know already! We don't. So after that my mother said, 'Right, well that's it - you're not going there anymore'. So I left that special school and went to a mainstream school for 8 years. Normally you go for 7 years but I stayed on for another year because of my disability. How did I find it? Well you catch up on all sorts of things and I can remember around that time that I was wearing plastic

glasses. It got frustrating for me because I couldn't see the blackboard. So in the end I needed proper glasses. I made lots of friends there and I still know them now.

From primary I went onto a mainstream comprehensive school and made some more friends. I came out with 3 CSEs - I did French, Drama and housecraft. I did grade 3, 4 and 5 in all of them. I also did an exam in typing so I know how to type, and I also had piano lessons. I learnt the piano for about ten years and after that I played the guitar too. My mum paid for the lessons, which was good for me. I was there for 5 years instead of 6 years. I made some good friends, but then I get this thing after five years from the headmistress saying to my mother behind my back, 'Why is this Mongol person in my school?' I felt really angry, very angry. Well, the moment my mother heard that, bloody hell, she went to the high court of justice and *we* won, the headmistress lost - because you don't say those kind of words really. I think we sued her, because my mother didn't want that saying about me really. The headmistress' attitude was that I shouldn't be there, but what was I doing there for five years? Going off to France because I was learning French, you know and all that, and I get that at the end of it.

After that I went to another special school. I went from a mainstream to a special. Silly isn't it really. I was 18. That's how I met another friend Jennifer, who I still know now. She was at a mainstream school although she also has learning difficulties. She doesn't class herself as being one, but I know she is. She has learning difficulties, its the way she speaks, the way she does things, which is slow, you know. Anyway the trouble was she was bunking off school all the time because her mother was dying. That happened when she was about 12, and because she was doing it all the time

she didn't really do her work in school. So when these two social workers saw her, they said, 'Okay we'll do it'. So what they did was to take her by the arms and put her in a special school, where I was, in the same class. And that's where I met my friend Jennifer. I met this other friend as well but she was a bit stroppy actually!

I didn't like it at all and only went for a year. The mainstream school was a lot better. Although I had one or two mishaps there, one boy pushed me in the playground crushing all my fingers. Someone else spat at me down my back. In my special school everyone picked on me all the time - none stop - either because I had Down's Syndrome or I was the odd one out. I am too bright to be in a school like that because my Mum brought me up in her natural way. To be as normal as possible. So these other teenagers were totally backward basically. I remember this other girl, Brenda, I remember her well. She was really naughty and it was very bad what she did to me. One day she poured boiling custard right down me. It was total craziness to do that. She thought it was very funny, it wasn't funny. I was crying and she thought it was funny. Stupid twit. So in the end I left. I couldn't stand it. It was a huge mistake of my mum putting me in that school. There was one time when the teachers and the headmistress were talking. Middle class 5 were throwing plastic cups at me. I stormed up and I said to the teacher, 'Can you tell them not to do that'. She never did, she still kept yacking away to the head teacher, totally ignoring me. I thought, well, this is lovely isn't it? I thought, well, this is it and I've had enough - goodbye. So I was there a year and I left straight away.

Then I went onto a mainstream college and I did a pre-vocational course in office skills. When I was still at that college, I had an interview for another

college. First they suggested a course on 'community care' and I thought, well, that's not what I want to do. I thought that's a bit silly. I looked down the list and it said 'food'. So that was it, 'Yes', I said, 'I'll go for that one!' So I did a food industry course in catering in the end with both colleges. One of them is very famous for catering and I did that for about 2 years as well as a general course at the other. I became a chef, a waitress, I did a project on continental foods, Swiss recipes, German recipes, French recipes, Italian recipes and they were totally thrilled with my work. I laid on a tea for my mother. She came in and it wasn't like a cup of tea, there was more to it than that, it was sandwiches and cakes - 'high tea'. She loved it. I showed her my work, she enjoyed that too, she was very impressed with my work. I also went into hotels, Claridges, the Dolchester, big hotels, and after that I started working in '84.

Starting work

I started working with the Down's Children's Association. I was 21 and I met my first boyfriend there, Paul, who I'm now back with. When I first started in '84 it was the Down's Children's Association, children only, but now its spreading out. It's called the Down's Syndrome Association. I was there for ten years. I was very popular. I was on the TV and radio. I was there when my mother was dying. I took a week off. Also when I was there I had my accident in 86 - 87. I was run over by a motor bike. I had a broken shoulder, collapsed lung, broken ribs, you name it, not in a pretty state at all. My mum heard and she was in total shock. I was rushed into hospital. There's also another bit I should come to. When I was lying on the ground waiting for the ambulance for 20 minutes, I was conscious throughout. I felt a blanket coming over me and after that a lady walked up to me and I

remember her asking, 'Why is this Down's Syndrome person walking on her own?' It's inconsiderate to say such things. I mean I have to do things on my own. Who would do it for me? No one. Because my mother's not here, I have to do it for myself. Paul won't do it for me. Soon afterwards I was back at work and they wanted me to do lots of things like hoovering and taking heavy parcels to the post office. I told them, 'I can't do that, I've only just got out of hospital, for god's sake, I can't carry heavy things with this arm'. They were actually using me as a dog's body, they weren't using my skills.

If you have a Down's Syndrome baby, you have to know the right things to do, keep it warm, keep it clean, give it love and care. The problem with that lot was that they'd never had a Down's Syndrome baby. 'Normal people' were in the association, I was the only one with Down's Syndrome working in that office for 10 years. None stop. There was also at one point going to be a fund-raising event, a ball, and I had my mind fixed on a nice dress and lovely shoes. Then I get the office manager saying, 'Anya can't go because she ate at the wrong table', because I was eating my lunch at the wrong desk. I think that was so stupid. Here I am because I've got Down's Syndrome, I will give publicity to other people like Marti Webb and those mega-people who were there at the ball, and they don't let me go. I could have given them publicity about Down's Syndrome because I have done and I know. I can, because I have Down's syndrome, others don't, they don't know what it's like to have it. Who has 47 cells? I have. They haven't, they've only got 46!

I stayed there for ten years and I left of my own accord. When my mum was dying, they wanted to help me. They saw me sitting there doing nothing, so

I said, 'Right, I'll do something about it' and left. I moved onto another job at this Society for the Mentally Handicapped - which is learning difficulties. It was an office job, but again they didn't use me for my skills. I used the typewriter, but not much, so I asked to use the phone. I use the phone at home - it's easy. So I started taking phone messages, photocopying, everything, I really got into it. I was there for a while and I thought they were pushing me out, but they weren't, they were moving me up. So they promoted me higher to work with a self-advocacy group. I had to apply for the job and it said on the application form, 'Why do you want this job?' I thought, 'Go for it, you can speak up for yourself', so I went for it. At the interview it was like a kangaroo court, beginning to end. There were all these workers and supporters and they were all looking at me. One of them, Peter, his eyes were sparkling at the time, because when I got the job, I became his girlfriend.

Speaking out - in a group and on your own

I started in 1993, the day after my sister's birthday. I was the 'Young Development Officer'. Going everywhere to places that I'd never been to before. I was giving sessions up and down the country, talking about safe sex to kids with learning difficulties. Everyone had a support worker and a co-worker to work with them. Like, Julie was in a wheelchair and she had her support worker. There were, like, workers, self-advocates, and non-workers who are normal people, like James, Carol, and Luke. The supporters help you to physically do things. They shouldn't bite your head off all the time, but everyone was doing that to me.

They did help though. If I went to conference they'd do all the writing and I'd do all the speaking. We did a video about first time sex education. It's about this couple, Julie, and her boyfriend Chris, and she wants to know about having sex and a relationship. I mentioned that in my own film, 'First Sex', which was shown on Channel 4. I mean Down's Syndrome people don't know what it's about sometimes, to have a boyfriend and all that. I mean, here I am living alone in my own flat and I do stained glass, which I sell. Sometimes people don't know about being independent. I don't think many Down's Syndrome people know how to do stained glass. They don't have my skills in other words.

I've done conferences on Down's Syndrome. I came up with the history first before I started. Originally the guy himself, Dr Landon Down, started it off. He was based at Richmond in the Norman Field hospital. I remember seeing a sculpture of his head. A very amazing man who actually invented the word Down's Syndrome. It was him who got the word going. From that I got all the history, some from the Down's Association and some from the Open University. It came out very well at the conferences. I brought in other things like plastic surgery and sex. Sometimes people with Down's Syndrome don't know about their sex lives, they don't know what it's about, having Down's Syndrome, or what its like, because people get floppy armed, double jointed in their hips and other things. I hate the words 'plastic surgery', totally, because we all have different faces. Why do you want to destroy it? I mean look at Michael Jackson, it's disgusting. I really hate that, I really do.

I went to a conference in Barcelona to talk about testing on Down's Syndrome. It was a massive conference, with doctors, researchers you name

it. It was terrible, really bad. They didn't have a meaning of why we are human beings, and they should know the meaning of a human being. We're not animals, are we? When I was on that stage I really gave my mouth to them, I really did. Everyone had these earphones to listen to their interpreters and I actually said to them, 'We are not guinea pigs we are human beings'. They were looking at Down's Syndrome babies from the age of two, and they were testing on them, it was preposterous. I mean, how dare they do that to us? treating us like guinea pigs. This year I'm off to Helsinki, which is about technology and Down's Syndrome, and I'll be speaking up then. I mean, in my day it never happened. If you had Down's Syndrome you couldn't do anything about it.

The term 'Down's syndrome', is okay, but its like my Dad said to me, 'You're not Down's syndrome, you're 'Up syndrome'!' I remember when Speaking Up groups went to Canada in '93, I had to do a poster on different labels and names - 'retarded', 'handicapped', and so on, until there were no labels at all - just your name at the end. I mean, it's silly using a label all the time. You can't say you're 'just handicapped', because you're labelling somebody and that's not the way to speak to someone. Like on TV sometimes you get people saying that all the time - 'You're handicapped, you're handicapped', when you're not. It's like sometime back, I've got an article on it, in a 'Touch of Frost', there was a young man who had Down's Syndrome. He was getting married to his girlfriend who also had Down's Syndrome and they went upstairs to a bedroom. Even the man in 'Touch of Frost', David Jason, and the other bunch of people were saying, 'Why is this handicapped person doing this?' It was a murder case and they thought it was him doing it, but it wasn't, yet they frame him, the person with Down's Syndrome. Same in 'Brookside'. They don't show Max and

Patricia's baby because she has a Down's Syndrome baby. They show it negatively because they're not showing the baby much, are they? We see the people but we don't see the baby - where is the baby? Its the same in 'Neighbours', Cheryl's got a Down's Syndrome baby too, even though the baby doesn't look like it has.

The label learning difficulties. Do I think it's a good term? It is actually, yes. That's the new version, it's the same as using Down's Syndrome instead of the old term. It's good to use so that everyone can recognise the term. This lady who had a Down's Syndrome baby, he died when he was two, and she wrote a book about it. It's a true story and she's been on TV twice and I know her very well. She's a lovely lady, amazing, and she was totally thrilled when she met me because I have Down's Syndrome. She really wanted to see someone with it. Would I say I have difficulties learning? No, I learnt well enough. I picked up things very quickly.

Leaving and looking back on the group

When I was in the self-advocacy group I was being the star and they hated it. I was going on TV, I was on the radio, in the papers, even with my conference I did on Down's Syndrome I was in the Guardian. You name it and they were jealous of me. I remember going off to do 'UK Living' or something. They were jealous of me, because I'm bright, I can do all these fantastic things, I'm too clever for them. I know what's good for me and when I left, they lost a good person, they let me down.

I left for a number of reasons. It's difficult for me to tell you. I can't give the details, I said something I shouldn't have. I meant to say one thing but

another thing came out of my mouth. That was my mistake. I did that, but we all make mistakes. I was only worried for the members of the group. Other people over-reacted. My second mum, June, said they used me as a scapegoat and gave me abuse. They did. Nasty piece of work. Then there was all this stuff with another member of the group. They accused me of doing something that I didn't do. It wasn't fair the way they treated me. You need discipline and your independence, I mean I had those from my mother. When I was young, I went to my friend's house and came back at 11 at night. I rang my mum to say I was coming home. When I came through the door I got disciplined sternly from my mother because she had been so worried. I learnt my independence and my discipline together. I don't need discipline from that 'speaking out' group. That's what I don't need.

Being in the group was worthwhile because I was actually doing things. Using my skills. It was good and bad. A bit of both really. Having the job and using my skills, going out and meeting people all the time. We did one session about using drama to speak up. People who were there really enjoyed themselves, it was brilliant. It was okay until that happened at the end. No job to go to, what was I going to do? Sacked totally sacked. It's a good organisation but they should have helped one another out more. They haven't really spoken to me since. It's very strange really. I was sent this folder about 'services' and on the bottom is 'speaking out group' and I thought, 'Oh this is lovely', they send me this stuff and I was there when they were writing it. I'm in the folder myself. There's a word that the group doesn't like - 'respite care'. Now they don't like that word and there I was trying to promote it. It's good to have 'respite care' for young people, to get away from their parents, its respite for both. I mean I still have respite

myself, though I haven't had it for a long time, and it does me the world of good to go away for a little while and come back into it again. It did my mother the world of good. For young people to have it is the best thing really. It's for both the parents to have their break but also for the young people to have their break, to do what they want to do. But the group didn't like it you see. I was meant to be on a management committee for 'respite care' but they didn't want me to do it. 'Do it in your own spare time', they told me. We were at this conference, and I said to them all, 'You're always thinking of yourselves, me, me, me, what about other people?' I really put them in their place They were all complaining at me, and I thought, 'yeah, I can put my person into it now. You listen to me now, I've got my say now'.

There's another word they didn't like - 'bereavement'. But you have to go through it. My mother died, right, I had to see a counsellor, I needed that. When a great friend of mine died, she was like a third mother, I was in a total state of shock. I couldn't go into work. They were telling me to come into work. They must be physically mad when I was in a state of shock. I couldn't go in. I didn't want to anyway, crying my eyes out, and they said come into work on the same day. They even phoned up to see where I was. They didn't even pay for me.

Family and the future

There's this woman I know with learning difficulties. She got her independence by passing her driving test, and she has her own car and a telephone inside it. Lovely girl, long blonde hair, very skinny, quite shy, lovely parents. We went to see her, me, and my second Mum. June said, 'Right, Anya you'll have to drive too'. But I thought, 'No, you can't say

that June, you've got a car, I haven't'. You've got to learn the skills to drive, have your car parked outside, there's lots of difficulties and it's lots of money. I mean there's buses here and I have a free pass. Mind you, I've been waiting for my pass for a month now and still haven't got it, it's ridiculous, it really is. I mean I'm forking out £2.60 for a return to my drama class.

It's like getting married. My neighbours keep saying, 'Come on, you've a lovely flat, how about getting married'. They even said to Paul, 'You've now turned 43, you can get married'. I thought who are you? It takes time to get married, it's a big step to go through in life. Things can wait. I'm young, I'm 34 and I'm single. I have my independence. It might affect my benefits. I mean that all comes into it. For me, there's still lots of things to happen. It might take a little time to get married because it takes a long time to get organised before that. I want to get new things in, new clothes, a new ironing board. They come in before all that stuff.

My Dad said before he left to go back to America, 'I will do it for you Anya, if you want to get married, I'll do it for you'. And let him do it. I won't do it. I haven't enough money. I'm unemployed. So's Paul, he's unemployed, even though he's got a little job he hasn't got much money because he's only doing it voluntarily. So if we do want to get married eventually it will take time, but my father will have to pay for me. He's loaded - he's an artist. He lives in New York. I went over once to see him when I was 17 with my mother. It was okay, but I would never live out there, it's better here. I had a phone call one morning from my Dad's girlfriend, saying your Dad's here in England. I thought that's funny what's he doing here? Strange he didn't ring me. He just came round to my house

and he was having an argument with his girlfriend. I said, 'If you're going to have your argument then have it outside, I'm not having it in here'. I hadn't seen him for 6 years. I told him, 'My mother's dead, you didn't come to the funeral, no flowers, so what are you doing here? You didn't care about me then, did you?' He didn't say anything about that. Been on the alcohol again, after all these years, after my mother got him high and dry, back on the booze. I got away for a little while to see my second mother, June, and when I got back on the Monday morning the whole place was in a mess. So I say to my Dad's girlfriend, 'Okay, get out there and get a pint of milk'. She was bossing my Dad about and I said, 'Look I'm the boss not you, because I'm the boss of this flat'.

I've known Paul for 10 years. I met him through country dancing, which is a really nice thing to do. It was on a country green outside Oxford. My mum knew what was going on! She knew Paul. We split up for a time. When my mother died, he didn't make it to the funeral. Then, some time after my sister bumped into him and invited him back for a coffee. There I was, just about to go to bed in my nightdress, and he came in. He told me, 'I should have been there at your Mother's funeral'. I asked him, 'Where were you? Because you should have been there, because you knew my mother', I told him. But his Grandmother wouldn't let him go. She said all sorts of things about me. She was against me. Later she apologised. It got well out of hand with Paul at the start, but I was in love with Paul, I was pushing him to stay over with me. So he said he'd ring his grandmother. I was pulling him one way and she was pulling him the other. I said, 'You should show your grandmother what you can do for yourself, show her you have your independence'. She died in '92 but now he's got his independence. She always had him under her wings. Little baby boy in the school cap and

all that stuff. It took her a long time to see him as a grown up man. He was 33 when he first knew me. Silly, because his parents had split up, his father lives in Monte Carlo in the south of France and his mother lives in San Diego. She actually sent us some presents last Christmas, really nice of her to do that. We also sent the video of me and Paul - the 'First Sex' one. She's shown it to all her friends.

The time when we got back together. That night I went to see one of my friends. We had a Chinese meal together, and on the way home, on the train, there was Paul on the platform talking to his friends. So I got off at the platform and thought, 'Hello, what are you doing here?' And the one thing that I said to him, those magic words I used, 'Come back for a cup of tea'. It was more than a cup of tea! That night we got back together on the 24th April and we've been together ever since.

Children are something I'd consider in the future, not now, very much in the future. I mean I've got three nephews, one niece and one god-niece and that's enough. I mean one, she is four, and she is a little monster and very bright! She wants everything, she wants the lot, like in the Argos catalogue. She can want it but she can't have it! I'm on the management committee of an organisation for children, five or under, with learning difficulties. I've said to them that they have to use accessible language, with words and pictures.

Words of advice

My advice to people with learning difficulties about self-advocacy? Try and speak up, get what you want in life, get your voice across. I think self-

advocacy groups can help you do that. Even now, when I bring things up about self-advocacy, I tell them about my old group, but I do tell them not to mention my name.

Phillip Collymore - 'It is true. I know it is'

Phillip was institutionalised in the mid-1960s and subjected to physical, mental and sexual abuse. He wanted his story to be read by others. People First 'set him free', as he put it, and he has been group treasurer for over a year. He has made quite a name for himself as an advocate for others with learning difficulties. He contributes to his group's newsletter, has represented the group at numerous conferences and recently spoke with members of his local Council about the unnecessary use of jargon in leaflets about services. Self-advocacy changed Phillip's life by equipping him with the confidence and words to speak out about things close to his heart. At the time of writing, Phillip is the key complainant in a case being brought against the staff who abused him and many others. He collected the names of his fellow 'patients' who said they had been abused and presented the long list to a service manager. Many of the victims are unwilling to go to court, others have been deemed as 'too weak' by the police. Phil is the main figure in the trial. He now shares a flat with his dog and a friend who is a fellow ex-resident of an institution . This is Phillip's story:

Institutions to homes

I haven't had an awful lot of opportunities for work but I have done work in the past. Clearing up, dusting, and all that business. I've done household work, gardening and farm work. There used to be a farm where I lived which they're pulling down now. They're using the land for houses. It was run by a charity. They had an awful lot of farmland there and we used to look after it. There was me, Tommy, Peter, Arthur, about 5 or 6 of us. I was there for 30 years. They ran it how they wanted to run it. They didn't let

you have a say about how it should be run. It was for people with learning difficulties and some of them were really bad with learning. The staff really took over - 'You can't have this, you can't have that'.

It was for men like ourselves with hospital staff looking after us. The hospital staff, they could be a bit on the 'bent side' - if you know what I mean. That was a problem. They took it out on the lads who were there. That's why the majority of men don't like the hospital staff. We took them to court over a few things as well. They got fined for what they were doing. They're not running here any more. They've gone abroad, but they'll be doing exactly the same over there. I moved there in 1966. Living there was hard. I got knocked left, right and bloody Centre. That's why I was afraid to speak up. It was very hard for me to say anything I wanted to say because if you're not big enough to fight, then you'll get a hammering. And if you're big enough to have a fight, you're all right. If you can stick up for yourself, you're okay, if you can't, then watch out.

Sometimes I couldn't stick up for myself at all. Every day I was getting beaten. There was not a day missed out without me getting a good hiding. Then I would be getting raped and all that business. People don't realise it. It is true. I know it is. The people out there experiencing it, they'll tell you that it's true. Others will say it isn't. But these days you've got to look at it. People who have been in homes all their lives will tell you it is true. The outside people have never been in - they won't. Now I know they're the ones who are in the wrong, not us. We paid their wages, but once they got money in their hands they could do anything with you. They were in charge of you. They could have you walking round the home all day with no

clothes on. They used to say, 'We're over you'. As long as they're over you, you've got to do as you're told.

Same with bath nights. There was only two baths in the place. The whole lot of us would get bathed in them on one night. So every man's waiting and they've all got no clothes on and they're all waiting in this big line outside. Bathing in the same water. Some of them had bad skins. Bathing in the same water every time. Now since I've come out of there down to *People First*, I've come out an awful lot. I've told people since. There's been compensation but it is awful what they've done. If that wasn't bad enough, I ended up being in another place that was even worse. This other place was even worse because the staff would do things what the hospital staff would do. You'd get raped left, right and Centre in that place. Until I started going to an advocacy group, which set me free, I couldn't put my views across, tell people what I thought of them, tell the DHSS, tell anyone. I couldn't tell the staff where they were going wrong.

I'm living in a flat now. There's only two of us there. When I moved my stuff in, I moved some of it into my house and some of it into a spare room. There's a spare bedroom, you see. The bloke I share the house with, he was in that home as well, where the hospital staff were. He got taken from his family and put into a home from the early 60s. He'd not seen his family for 20 years and now he's only just started to meet them again. He's about 53 and he'd never met his family at all. I've got family, but they're living abroad. I've got Aunties in New Zealand, one Aunt in Essex - that's about all. So all my family are nowhere in England apart from the one. Last year we had a flood in the flat and we had to move out and go to another house and we had to wait six months until it had dried out. They had to re-

decorate it, put it back, but its not even better - they haven't even got the beds, you know. I've got the dog to keep me company. It's a different thing now. It's no longer, 'You've got to be in at 9 o'clock', coming back as soon as you've gone out. Now I can please myself, though I've got to be careful what I'm drinking, medication-wise. I look after bills and all that. I'd never seen a bill in my life. I wouldn't have known how to pay it. I'd never paid one in my life. I'd never been taught how to pay a bill.

With the flat I'm in now, I was moved from pillar to post and I had no say in it. They moved me from house to house. They wanted me to move out of these houses because I was telling them what to do. Back then - I wasn't given a say. People are being given a say now but, then again, people were not being given a say in them days. With it, people didn't know which way to turn. They only had a certain way to go. People always asking, 'What are you doing?' 'Where are you going?' It's wrong. And now, people have the right to say, 'I want this and that'. If they have the money they'll get it. I think it's good for them. It's good for them to see us and see how it is working.

People First

I started *People First* about four years ago. The place where I lived, I'd been there since the early 60s, started up an advocacy group. So I went along. I just wanted to see what it was all about. It was all right. Then Jackie and Guy from my present group came down, one evening when we were having a meeting. I didn't know them. They were starting up an advocacy group and they wanted me to help out. I thought, 'Fair enough', and I've been in this advocacy group ever since. When I started off with

People First I found it awful hard because I didn't know what to say, how to say it and who to say it to. I was afraid of people. Now, I could tell you about the past, the future in 15 years time, how I'm going to cope, will I cope. I didn't have any idea how to speak out until I met *People First*. Other members helped me. Guy was chair for about 8 years and now we've got a chair and a vice. He helped out. Others gave me confidence. Guy says, 'Look, do you want to say anything? If so, shout it out. If people tell you to shut up say, 'No, I won't. I'll speak like I want to speak not how you want me to speak''. I've got a loud voice and if you don't like it you can lump it.

People First is good. You can get your views across. It's still happening all over the place. And it will happen all the time. You get a young kid, a young girl or boy, they'll go to that kid and have sexual intercourse with them and nothing's been done about it. What you've got to look at is the kid's point of view. They've got to have their point as well. They've got to have their rights as well. I would give the rights to the kids. What you've got to look out for is they can have too many rights and all of a sudden they blow up on it. Kids are very vulnerable. *People First* has helped me out an awful lot. I think the set-up's good. It's helped to bring me out of things that I wanted to be brought out of. Wendy's helped us out, Rachel has, Guy has. People like that have given me a push. Like they say, 'You're not doing that right, I'll show you how to do it'. I think going to different places, like conferences and workshops, has brought me out an awful lot. It's helped me to speak up, what to say and how to say what you want to say. How people with learning difficulties should be involved in it, not just staff. I'm the treasurer. Looking after the money, signing cheques, how much has got to be taken out or put back in. Where and how is it going to be sent. They want to know where all this money is going. I enjoy it. I've been treasurer

for a while - I'm getting there. It helps getting food, buying a pair of trousers, why not get socks instead of trousers. I was voted in by the group. If I'm not doing the job properly, they tell us and I want them to tell me.

We've been campaigning, going to trade union Centres, going to the town hall, trying to get money off them. Then we go to other advocacy groups, and disability groups to get money for Wendy our supporter. We're going to get more money if we can for the office. See if we can keep our organisation going and to see if it will work out. We find it hard, it's difficult, but it gets us out. I think it gets the men and women out. They've done a lot of good. They're learning how to say no. Now if you said something to me and I didn't agree with it, I'd say, 'Hang on a minute, I'm certainly not doing it. You're wrong on that. Let me tell you the other way, see how it works out on that'. And we'd try my way. That's how we do it. Instead of keeping their mouths shut, they've got to learn how to say no all the time and yes when they want. That's what the group is about, the supporters can't do nothing about it, we're paying them after all.

How do I find the advisors? Some of them can be a bit pushy and some of them can be a bit bossy. But they do say, 'Well, you're paying my wage so you've got to tell me what to do'. These are the advisors and we're telling them what to do. It's good. Now some of the members don't do that yet but they're getting there slowly.

The Advisor comes in and writes down the minutes. We don't get the advisor to say anything - she'll type it up in the office. If there's a mistake, we get them to write it again then send it out to the members. I think the supporter should be an outsider. People should say, 'Hold on, we don't want

a member of staff as advisor because we can't say what we want to and we can't say a lot. We want an outsider to come in to the group'. I would go along with saying get an outsider, not a friend but someone off the street. I don't want the staff to do it. I'd tell them, 'I don't want you to tell the staff what we've said'. They'll get funny ideas. But then again we tell the bosses what we think of them, what they're doing wrong. When they're supposed to be working towards something and they're not doing it, why are they doing something else and not the other? You get paid to do one job not two jobs. We've got every right to tell the support worker what we think. That's the best way. We're the ones paying the staff and if the staff cannot handle it, well, they know where the gate is. That's why they wanted me out of the house, because I started telling the staff what to do. I didn't do it before - I learnt it off *People First*. I took my ideas from the group up to the house where I lived and said, 'Hold on, we pay you. If you don't like it you know where the door is'. They used to say, 'Oh god, here comes Phil!' I've still got friends up there and they tell me what's not being done. I'll take notice of the service users before I take notice of the staff - that's me. Because I know they tell the truth. I know they are. I'll find out if they're telling a lie. Then I'll go back and say, 'They tell me you're not doing this job properly, why aren't you doing it properly? You get paid to do this job properly'. The majority of staff don't like me for saying it. But if they don't like it, that's their business. Why don't they do the job properly in the first place? There's a lot of unemployed people who would do their job as good as them. We pay them. If they can't do it then that's it. There'll always be aggro with the staff because they don't like to be shoved around. They can shove us around but we can tell them where to go - us service users.

Changing Services

We went to a conference last week and we said there should be more for people with learning difficulties, not just for members of staff, that way it would be a lot better. And it would be easier as well, both sides getting the picture and with that they can see how it can be worked out with staff and with people with learning difficulties. We should be involved with the services and when we are they'll realise. It will be a lot better because we'll be learning off each other. The majority of staff can't see it in that way. The majority of staff will say okay, but when it comes to the crunch they won't do it at all. All talk - no action. With that they are not learning nothing at all and they should be learning an awful lot.

We went to the Town Hall for the launch of a guide written by the local council. We said they should have people with learning difficulties on the committee for planning services. I think they'll learn an awful lot from people with learning difficulties because they've got a lot more experience than those people in the town hall. It's all right them saying they've got loads of ideas. They sit on their arses and say that but are they getting their ideas from people with learning difficulties? Are they paying them? How are they gonna get someone in the office, to see how they work, put their ideas together? They'll learn an awful lot, not big bosses sat around a table saying, 'We'll do this and we'll do that'. If you look, it's people with learning difficulties' lives. What you've got to look at is getting two people with learning difficulties on that council saying how its working, not talking jargon, but asking questions. I tell you something you'd be a lot better off. Everywhere you go they're using jargon and there should be a leaflet out saying no jargon should be used at all. If you can't not use it then don't talk

at all. What we've been doing is writing letters to people and saying, 'We don't want no jargon in letters, talk. If it's a lot of jargon, it's a lot of crap'. Often people don't know how to speak, they haven't the faintest idea how to. If you can't speak - shut up. I would tell the council. I think I could put them in their place. I'd say, 'Shut it'.

Mental impairment? Now what the hell's that? Never heard of it. I've heard of learning disability. I think mental handicap is still being used but they shouldn't. We've been going through our MP, we've been writing to say that those hospital staff still use mental handicap. Why are they using what they used to 20 years ago? When they're getting the money they can call us what they want, which I think is all-wrong. I think for ourselves, we are men and women, and we should be treated as such. You are a man or woman, then why not call us men and women? I think its only fair. Just because we have learning difficulties, but then again we can get there in different ways. Maybe we're slow but we'll still get there. I think we should drop all labels because all labels have gone by the book. They're still flagging us down as learning difficulties, but we are men and women with a learning difficulty. They are still keeping that name, mental handicap, so they get money off the government.

People on the outside

You've got to keep reminding people - especially people on the outside. You know, like mothers, families, you've got to remind them all the time that we are different to what you are. Which, fair enough, we are different. We've all got our own ways of living. Education is important, especially with young people. My experience of young people - they've got to be

trained. If a person has got a difficulty with reading and writing, or they have to have medication, they need to be helped by the other person. They've got to. Then he or she will grow up and have friends, but she won't have friends who are on the opposite side, like I had. If he or she has friends in the school then they can give them a push. Like say, 'Come on, let's see if you can do this'. As I see it, it's young people's lives, they're the future, and they've got to do the best with it. If they want to make it good, they'll make it good. They've got to keep building on it. Make sure they've got a foundation on it. We didn't get told how to build a foundation. We just got thrown into a home and they said, 'Right, that's it, you're in there for the rest of your life'

When I went to my first home, I thought I was going to be in there for good. I didn't know how things worked in those days. They said, 'Oh, 30 years is a hell of a long time, you'll not get out'. But I told them I wanted to get out. So I went to psychologists and doctors. Headcases, bloody headcases they are. They sit around and tell you what to do, you're stuck in a chair, you've got staff beside you, you've got students all across - 'What's the do with this person, why's he like this? How is he like this? Put it on a flip-chart'. They're only students - what do they know? These psychologists - what do they know? When it comes to the push, they no nothing. They can read it, that's good, but doing it in the mind, they're different things. Summing up my experience of psychologists - nowt. Now doctors, well, some are all right, some are up for themselves. Doctors are able to keep you functioning but they seem to be going for money these days. Doctors have got to give people with learning difficulties a chance to talk. Say you got a doctor, what he says might go over my head. I'd say, 'Right, hold on a minute, why go over our heads. Why not say it to our face? If there's something wrong I

want to know, no need to go over my head. I want you to say what's wrong with me and tell me'. The same thing has happened with psychologists. They talk over your head - which I don't think they should do. They should talk to you and if they can't talk in front of you there's something wrong with them. I've had bad words with psychologists, they always talk over your head. They think they know everything. They don't know nothing. They think they're better than us. They come to see us and they'll talk to the staff but they won't talk to us. But if they come to see us, why don't they come to see us, instead of talking to the staff?

Choosing what you want

Now social workers, I've even had experience of them. They'll push you round from pillar to post. Some are getting better some are not. They'll just push you into a home where you're not wanted. With the house I'm in now, I wasn't asked if I wanted to move there. They just said, 'You're going into a home', and they got us into the house. I went to London that week and they said you're going to so-and-so house when you get back. I didn't even know where it was. If they're going to move anyone around they should ask the person. They should ask the person where they want to live, who they want to live with, and what staff they want in it. I think they should ask the person, 'Do you want to be moved, yes or no?' They should give them that choice. If they say no, then they should say, 'All right then, I won't move you, I'll leave you where you are'. If you say yes, they should ask, 'Who would you like to be moved in the house with? A man or a woman?' They should have that choice as well. They should have the choice of staff, male staff or a female staff. Would you like to have a pet? A dog or anything like

that. Would it be okay to have our friends sleeping over? Just like a normal person.

That's the way they should be looked at. They should be looked at as people with learning difficulties. As long as they have close friends, as long as they can go out in the evenings, as they long as they're able to say, 'Right, I'm going to the pub', 'I'm going to meet a lady friend of mine', that's the way I look at it. Like, I didn't have any close friends. I 'm only just starting to have a few close friends now. Before I had no close friends at all because I'd been locked up all my life. And when you've been locked up all your life, you can't have no close friends. With that it's hard to make friends. Very hard. Now I'm starting to make friends and with that I'm starting to go out in the evenings, and go the pubs and clubs and make friends that way.

Some of our men and women go into work and get paid, but what they get is little or nothing. If they get a tremendous amount of money, they get some of their benefits stopped. Same with me. I've had no real opportunities for work but I have worked. I had an experience in an office, I had a job the year before last, part-time like, and it was really good. I was pleased to get it. I've done gardening work, done farm work, done office work. That's the only kind of work I've done up to now but I can do other type of work as well.

Words for others and the future

If people with learning difficulties wanted to get involved like ourselves I'd say, 'Hang on a minute, right, you want to get involved, we'll put it to the

vote with our self-advocacy group first, that you want to join'. If they all say yes, we'll invite that person in, then we ask her want she wants to say, get everyone to shut up because she might be timid and shy. Let her break the ice. I think its good - that's how I started. I was awful quiet and they all shut up and listened. My first time, it broke the ice, how I thought about it, and how I thought it would work out. They asked everyone to shut up and I started to break the ice. My advice, don't get too worried, don't get too shy, you'll get confidence when you're speaking. If you want to speak put your hand up and we'll put it down on a piece of paper.

In the future I would like more money in our pockets, a bit more education and more ideas to keep the office working and the supporters. I would like to see this office to go for another 10 -15 years for our future. I'd like someone to say, 'Here's 20 grand to keep us going'. If we're still there then we're all right. What do we think of this generation. How is this next generation going to go? Will they tag along with us? I want to see their ideas. It's just a question of whether we'll last. If it does I hope so. I think it will.

Chapter 7

Learning from life stories - the lived experience of self-advocacy

Introduction

Life stories were collected to examine the impact of self-advocacy groups upon the lives of people with learning difficulties. Narrators introduced a number of themes that went beyond this original research question. This chapter explores these broader themes. The analysis falls into four sections. The first, 'Pre self-advocacy group days – the making of a self-advocate', traces narrators lives from childhood to adulthood prior to joining self-advocacy groups. The second, 'Being in self-advocacy groups – coming out as a self-advocate', examines the impact of groups on the continuing development of narrators' self-advocacy. The third, 'Learning from experience – expert advice on self-advocacy', draws together narrators' opinions on the workings of groups and the movement. The fourth and final section, 'Looking at stories – the self-advocacy group and resilience', considers a number of general lessons that may be learnt about life as a self-advocate. The life stories illuminate the struggles of narrators throughout their life courses and highlight how self-advocacy groups enhance self-determination.

(1) Pre self-advocacy group days - the making of a self-advocate

The life stories highlight a number of childhood and adulthood experiences prior to joining self-advocacy groups that appeared to be informative in developing narrators' self-advocacy. These experiences can be slotted into three main themes: family ties, inside institutions and outside institutions.

Growing up – self-advocacy and family ties

'I know I keep going back to when I was a girl, and the old days, but things keep coming back to me' (Joyce Kershaw, her story, previous chapter).

The life stories draw attention to the influence of family life on the development of narrators' self-determination. Three of the five narrators were brought up by single-parents, three spent most of their early childhood in their family homes and three shared their home life with siblings. Two narrators were still living in their family homes at the time of being interviewed. A recurring theme for those who spoke about their family life was the determination of parents. Lloyd Page's mother had told him that there was a place for him in the world. He and his mum, 'Went for it'. Jackie Downer's Mum was strong and a great source of strength. Joyce Kershaw's Dad was all for *People First* (her story, *Appendix 3, 5*). Anya Souza's Mother pushed for Anya to attend mainstream schools:

'In my special school everyone picked on me all the time - none stop - either because I had Down's Syndrome or I was the odd one out. I

am too bright to be in a school like that because my Mum brought me up in her natural way. To be as normal as possible'.

Defiant parental figures emerge in the narratives. Systems were challenged and struggles were shared with children. However, parents' fears can lead to tensions when children reach adulthood (see Flynn and Saleem 1986, Mitchell 1997b, 1998). Jackie Downer and Anya Souza felt the ambivalence of being encouraged and over-protected by their mothers. The transition to adulthood is often hampered by dominant disabled images of 'adult with learning difficulties as child' that enter familial relationships (Koegel 1986), along with the contrasting opinions about independence held by parents and children (Zetlin and Turner 1985):

'Sometimes people with Down's Syndrome don't know about their sex lives, they don't know what it's about' (Anya Souza).

'Parents are very scared to let go of their children. Some parents want to do but don't know how to – always looking at the disability' (Jackie Downer).

Both Anya and Jackie spoke with their mothers about their desires for independence. After separating from her husband, Joyce Kershaw cooked and cleaned for members of her family and cared for both her parents when they were ill. Notions of readiness for independence appeared to have been worked through in the context of the family.

Suggestions of class and cultural identities are also picked up in the accounts of family ties. Dates of birth range from the 1930s through to the

1970s. One narrator is black, one Irish and one-mixed race. Anya Souza's mother came from Prague, her father from India. Jackie Downer's cultural heritage is something she is proud of, as she thinks more and more about herself as a black woman. Joyce Kershaw reflects on the 'old days'. Post-war - when things were cheaper, with trips down to the local grocers past an old woman who used to sit on the steps of her home smoking a clay pipe (Joyce's story). The life stories pitch life as a disabled child in the web of familial identities. Disability was one of a number of identity and experiential positions held by narrators that appeared to have informed their understandings of self and others (see Stuart 1993 for discussions about race and Morris 1991, 1993a, 1996 on women):

> 'I had a little job in a fish and chips shop. My husband got a job as a
> bus conductor. Then he got a job as driver. We were married for
> seven years. Then he went off with my best friend. We had been
> friends since we were little' (Joyce Kershaw, her story).

Stories point out that narrators' identities were not framed solely in terms of disability in familial relationships. By contrast, Phillip Collymore mentioned little about his family or background. From childhood to adulthood his home life was an institution:

> 'I moved there in 1966. Living there was hard. I got knocked left,
> right and bloody centre. That's why I was afraid to speak up'.

This lack of family life may partly explain why he lacked conviction in speaking up for himself prior to joining *People First*:

'It really doesn't help a person's character the way the system treats you. One thing that's hard is that once you're in it, you can't convince them how smart you are ... you're so weak you can't really fight back' (Ed Murphy in Bogdan and Taylor 1982, p218).

While families and heritage were important in developing the independence and identity of some narrators, a number of other similar experiences came to play a part in narrators' childhood and adulthood, as indicated in the next section.

Inside institutions, outside society – resilience in adversity

'A lady came to our house. She said I had to go to this school near Liverpool' (Joyce Kershaw, her story).

All narrators have experienced institutionalisation. Lloyd Page was in day centres for 17 years. Jackie Downer was in special schools up to the age of 16. Joyce Kershaw spent her teens in a boarding school (her story and my story). Anya Souza spent a year in a special school against the wishes of her Mother. In the hospital Phillip Collymore had few close friends – 'because I'd been locked up all my life'. Stories of institutions describe a continuum of exclusion. At one end institutions are boring and devaluing places, just sat on your backside, doing nothing (Lloyd Page). At the other end segregation creates power inequalities which can foster sexual and physical abuse, attacking identity through psychological terrorism (Swain and French 1998):

'They were in charge of you. They could have you walking round the home all day with no clothes on' (Phillip Collymore).

These anecdotes have parallels with accounts documented in previous studies of long-stay hospitals, centres and special schools (Goffman 1961, Edgerton 1967, Braginsky and Braginsky 1971, Zetlin and Turner 1985, Potts and Fido 1991). In some small way the life stories contribute to the insider literature on the history of institutionalisation:

> 'The telling of their experiences by people who lived for years in the large, segregated institutions has been one of the most powerful arguments for deinstitutionalisation during the past 20 years' (Ferguson, Ferguson, Taylor (1992c, p300).

Institutions endanger the development of inmates' independence. Consequently, institutional practices and community care policies threaten to erase or reduce family ties (See Banton, Clifford, Lousada and Rosenthal 1985, Potter and Collie 1989, Morris 1993b, Swain and French 1998). It is common for many disabled people and their families to live in a kind of cultural prison of constant poverty and social control (Ferguson, Ferguson and Taylor 1992b, p13). Stories contrast experiences of family and institutional life.

Narrators also revealed the politics of diagnosis and incarceration (see Bogdan and Taylor 1976, Ryan and Thomas 1987 and Oliver 1990):

'My mother asked, "Is my daughter okay?" The Dr said, 'No, she's not okay, she'll be mentally and physically handicapped for the rest of her life' (Anya Souza).

'I didn't want to go but they said I had to go for my education. When I got there it seemed strange being away from home' (Joyce Kershaw, her story).

In special schools, 'You were labelled as soon as you got there' (Jackie Downer). The impacts on family life of social policy of yesteryear are picked up on in the personal accounts. For example, Joyce Kershaw's experiences hark back to times when:

'Institutions were organised for the reception of the imbecile and idiot class of defectives who in many cases suffer from *epilepsy* and physical infirmity' (Potts and Fido 1991, p11, my italics).

Previous literature has documented the effects of institutionalisation, such as low self-esteem and loss of identity (Goffman 1961, 1963, Edgerton 1967, Jahoda, Markova and Cattermole 1988, Craft 1987, Barnes 1990):

'Far from being alleviated, people's handicaps were increased by restrictions that stifled personal development and autonomy ... At its most benign, the system viewed patients as perpetual children and treated them accordingly' (Potts and Fido 1991, p44).

'I was stopped from speaking out. There wasn't anybody to listen to you and when I did speak out. I was shouted down' (Lloyd Page).

However, despite these effects of institutionalisation, the life stories lend support to the idea that constraints have the paradoxical effect of promoting resistance (Foucault 1975, Fairclough 1989):

'There is, in short, a space within any oppressive social structure where human beings can operate from their own will. That autonomy may be born out pain, or misery, out of the very forces that seek to extinguish it; but its resilience suggests the existence of a human individual separate and independent from the culture in which he operates' (Sullivan 1995, pp4-5).

Swain and French (1998) argue that because the voices of disabled people have been informed by their experiences of segregated settings, there are many lessons to be learnt from their accounts. For example, narrators' scepticism of authority may be seen as a consequence of their struggles inside the system:

'Psychologists and doctors, headcases, bloody headcases they are' (Phillip Collymore).

'The headmistress asked, "Why is this Mongol person in my school?" I felt really angry, very angry' (Anya Souza).

'I've got a bit of a negative view of doctors, nurses and professionals. You see, they don't listen to us' (Lloyd Page).

Furthermore, sceptics shout back. Joyce Kershaw told the staff to call her by her first name. For all his anxieties around people, Phillip Collymore remembers how he sometimes felt able to stick up for himself against the staff who abused him. Now staff are anxious when Phillip walks in the centre, 'Watch it, Phil's here' they say. Anya Souza reprimanded a teacher for not acting when she was being bullied. Experiences of exclusion may equip people with a sense of injustice and ideas about good and bad practice:

'There's a lot of unemployed people who would do their job as good as them. We pay them. If they can't do it then that's it' (Phillip Collymore).

Those professionals that had narrators' interests at heart are remembered:

'Some professionals are ... *professionals*, other are ace - they know where the users are coming from' (Jackie Downer, italics in original).

'A nurse said to my mother, "Your daughter will be fine, she'll give you pleasure". So I did' (Anya Souza).

Joyce Kershaw was encouraged to speak up by the nurses in her boarding school, Lesley the keyworker and the centre manager Mr Jones (her story). In Phillip Collymore's later days in hospitals he attended an advocacy group. Staff members were not all bad. These accounts substantiate Duncan Mitchell's (1997a) biographical evidence that patients and workers inside

long-stay hospitals suffer what may be termed a 'shared stigma', which in turn may promote resistant professional practice:

> 'Staff too are seeking new and better ways of meeting needs as we leave behind the uncertainties of the past' (Lawson 1991, p71).

Finally, the life stories highlight the friendships that were made in spite of the effects of institutions. Jackie Downer remembers feeling cut off from her friends when she left college. Anya still knows a lot of her peers from school. Joyce Kershaw used to play monopoly, cards and pool with her friends in the boarding school (her story). Now she meets with her mates for a cup of tea, in the coffee bar of the local bus station. Lloyd Page feels quite lucky having lovely neighbours. As Edgerton (1984b) illustrated, while institutional cultures stress productivity, 'client subcultures' (friendship groups) emphasise sociability, harmony and maintain self-esteem.

Outside institutions, inside society - resilience continues

> 'I'm living in a flat now. There's only two of us there. When I moved my stuff in, I moved some of it into my house and some of it into a spare room. There's a spare bedroom, you see' (Phillip Collymore).

The life stories stress how narrators' resilience continued outside of institutions. All narrators now live in the community. Two live with a parent, one with a friend, one with a brother and another with her partner. Four no longer attend centres and spend their daytimes with self-advocacy

groups instead. Institutions threaten to de-culturise inmates but the community offers more opportunities for meaningful lives to be led (Wetherell 1996, p305). Moreover, an increase in the self-confidence of people who have left institutions has been shown to occur, suggesting that institutionalised stigmatisation is reversible (Edgerton and Bercovici 1976). Community living can aid the development of stability and independence (Cobb 1972, Edgerton and Bercovici 1976) and is favourable to becoming:

> 'Drawn in and taken over, leading a life primarily in a service world rather than in the world shared by others in the community' (Humphreys, Evans and Todd 1987, p119).

However, narrators recall those times when communities were excluding:

> 'When I was lying on the ground, this person asked, "Why is this Down's syndrome person walking on her own?"', (Anya Souza).

> 'Another reason why I wasn't given a chance to speak out? Lack of community I think' (Lloyd Page).

> 'Children in the bus station shouting, "Where's your yellow minibus?" I told people to ignore them' (Joyce Kershaw – My story).

Moreover, surveillance continued in some professional-client interactions:

> 'They sit around and tell you what to do, you're stuck in a chair, you've got staff beside you, you've got students all across - "What's

the do with this person, why's he like this? How is he like this? Put it on a flip-chart". What do they know?' (Phillip Collymore).

When given a chance to make it outside, perfection is demanded and assessment is deemed necessary (Booth 1990, 1991):

> 'In the bungalow training, he is given marks out of ten for a tidy room, well-made bed, clean floors, etc. How many so-called normal people would be disqualified from a normal existence on this scale?' (Ryan and Thomas 1987, p82).

Despite these knock-backs by the community and interference by 'experts', narrators actively sought a place in the community outside of service settings. Growing up was hard for Jackie Downer – 'a slap in the face' – but getting a job in a library gave her confidence. Joyce Kershaw had always stuck up for herself even before *People First* (my story). Anya Souza enjoyed getting an office job that gave her more responsibilities. This desire of people with learning difficulties for a more normal life as part of society is a desire that is insufficiently heard, but nonetheless there to be listened to (Ryan and Thomas 1987, p160). Narrators do not describe communities as places of care but in terms of the various opportunities that are (or are not) offered such as work, independence and friendship:

> 'As long as they have close friends, as long as they can go out in the evenings, as they long as they're able to say, "Right, I'm going to the pub", "I'm going to meet a lady friend of mine", that's the way I look at it' (Phillip Collymore).

'When Stuart comes to see me I give him cigarettes. His foster parents say I shouldn't but I remember the days when I didn't have any money and he gave me cigarettes and other things' (Joyce Kershaw, her story).

The narrators recall some of the bad times that all community members go through, from losing a job, a relationship breaking up to parents dying. In addition, their narratives document exclusion in communities alongside their attempts to be included.

Reflections on pre group days

The life stories indicate that the lived experience of self-advocacy occurs in spite of parental fears and practices of the individual model of disability - diagnosis, surveillance and institutionalisation. Moreover, the determination of others, particularly parents, staff and friends, appeared to be informative in narrators' developing self-determination. Reflecting on the stories of 'fit people who were removed' into institutions, Potts and Fido (1991, p139) concluded:

> 'That side by side with a painful awareness of lost lives, we have also become sensitive to their humour, resilience and determination. Far from accepting their lot in life, they recognise its injustices and have eagerly grasped the opportunity to give their view of The Park and its history'

Similar conclusions can be drawn from the five life stories in this thesis. Despite disabling barriers, narrators' early experiences indicate that

resistance occurs before joining self-advocacy groups - in friendships (Taylor and Bogdan 1989, Goode 1992) and family (Simons 1992), throughout childhood and into adulthood (Daniels 1982, Mitchell 1997b).

(2) Being in self-advocacy groups – coming out as a self-advocate

Some of the seeds of narrators' self-advocacy were sown before self-advocacy groups were joined. In addition, narrators were asked for their experiences of self-advocacy groups. Four themes emerge with respect to the self-advocacy group: the origins of the movement, as a context for defining resilience, as a context for support and friendship and a place that offers practical gains.

Joining groups – origins of the self-advocacy movement

'In the early days, self-advocacy and *People First* grew mostly in America, starting off in Washington DC and in '84 self-advocates came to England from different parts of America' (Lloyd Page).

Narrators recollect the beginnings of the self-advocacy movement. Their accounts add to previous literature that has been written by people without learning difficulties (chapter 2). The stories provide other insights:

'It's no use asking some authority for what he thinks, well, let's not say its no use, but it's important as asking the people of the streets, in the streets, people that actually live in West Belfast' (Parker 1994, on finding out about life in the North of Ireland).

Three narrators spent their daytime in centres or homes prior to joining self-advocacy groups. Jackie Downer joined a self-advocacy group in her 20s, Lloyd Page and Anya Souza in their 30s, Phillip Collymore in his 40s and Joyce Kershaw when she was 55. Groups were joined in different ways. Anya Souza and Jackie Downer got jobs as self-advocacy workers. The arrival in the UK of American self-advocates inspired Lloyd Page to set up a group. He later left to join a group that he now works for voluntarily. Joyce Kershaw obtained some information from the centre manager and helped to set up a *People First* group in 1986 (her and my story). She meets with her group in her spare time. Phillip Collymore had been involved in an advocacy group that met in the hospital where he resided. Then Jackie and Guy from his present self-advocacy group came down and told him of their aims to set up a *People First* group:

'I thought, "Fair enough", and I've been in this advocacy group ever since'.

Groups started up in houses, centres and hospitals, providing the impetus for a larger movement to grow. Narrators remembered enthusiastic staff and parents who had an input in the movement's early days (as documented by Crawley (1982), Worrel 1987, p31, Dybwad and Bersani 1996). Also self-advocates encouraged peers to join groups. The beginnings that narrators remember have parallels with the origins of the UK disability movement (See for example Oliver and Zarb 1989, Shakespeare 1993b, Campbell and Oliver 1996).

Early days in self-advocacy groups - Groups as a context for defining resilience

'Until I started going to an advocacy group, which set me free, I couldn't put my views across, tell people what I thought of them, tell the DHSS, tell anyone. I couldn't tell the staff where they were going wrong' (Phillip Collymore).

Life stories depict groups helping narrators to recognise, understand, clarify and develop their resilience. Phillip Collymore found *People First* 'awful hard' at first because he 'didn't know what to say, how to say it or who to say it to'. He was still living in the hospital at the time and was afraid of people. Similarly, life got better for Lloyd Page when he heard of *People First*. Initially, groups provide members with opportunities to formally and publicly recognise their voices. This is an important factor for oppressed people who are often unaware of their rights or their voices. As the Canadian self-advocate Pat Worth puts it:

'Before *People First* I had no reason to live. Now I have a reason for getting up in the morning' (Yarmol 1987).

Groups can exist as forums in which members speak out to others who listen. As the earlier experiences of narrators indicate - self-advocacy is nothing new but listening often is (Worrel 1987). As Joyce Kershaw puts it:

'In *People First*, we share our problems' (her story).

At first, this can be quite threatening:

'What you've got to look out for is they can have too much rights and all of a sudden they blow up on you' (Phillip Collymore).

Jackie Downer advises new members, 'To start with basic stuff first and campaigning later but you don't have to. You can just chat'. Phillip Collymore prescribes a softly-softly approach at first:

'Don't get worried, don't get shy, you'll get confidence when you're speaking'.

Attending a place where speaking out is supported, emphasised and to which importance is attached may be a novel experience for some. This may explain why Phillip Collymore initially found *People First* hard, because he had had few opportunities to speak out and to be listened to before. In other ways groups built upon narrators' previous experiences of resistance. Narrators began to formally recognise and articulate their experiences:

'You don't need to go over the top organising pictures, theatres, parties, meeting with other groups or self-help groups. Basic stuff first and campaigning later *but* you don't have to. You can just chat, you don't get the chance in the centre or at home' (Jackie Downer, italics in the original).

Groups provide a material outlet for self-advocacy. The confidence gained with group membership can aid the transition of self-advocacy skills into

other contexts such as IPPs, home and workplaces and at formal set-ups such as user-participation meetings (Barnes and Wistow 1992a):

'People have changed so much' (Jackie Downer).

Groups as a context for support and friendship (and tensions)

'Guy was chair for about 8 years and now we've got a chair and a vice. He helped out. Others gave me confidence. Guy says, "Look, do you want to say anything? If so, shout it out. If people tell you to shut up say, "No, I won't. I'll speak like I want to speak not how you want me to speak"". I've got a loud voice and if you don't like it you can lump it' (Phillip Collymore).

In Todis' (1992) study of Wilbur and Grace, a married couple with learning difficulties, Todis suggests that what each found supportive about their relationship was that the other was thoroughly familiar with the life circumstances that result from having 'development disabilities'. Similarly, life stories highlight the affiliations that can develop amongst people in the context of a self-advocacy group. A supplementary source of support was offered. The best friends Lloyd Page has ever made were the friends in the office. For Phillip Collymore:

'When you've been locked up all your life, you can't have no friends. Now I'm starting to make friends'.

These support networks gave narrators valued roles and relationships in which to work together on various issues ranging from, for example, when parents became over-protective to service abuse:

'I can take a risk, I can have a relationship ... I can cry if I want to cry' (Jackie Downer).

'People First has helped me out an awful lot. I think the set-up's good. It's helped to bring me out of things that I wanted to be brought out of' (Phillip Collymore).

In contemplating the prevention of sexual abuse of people with learning difficulties, Craft and Hitching (1989, p9) observe that many people with learning difficulties have to do what they are told in care settings:

'So that obeying someone comes to be equated with being good. A great deal of corrective work is needed to help students see themselves as valued individuals who, like anyone else, have personal preferences and rights'.

Self-advocacy groups may provide contexts for self-correction. Nevertheless, as with all collectives, groups should not be romanticised. In-group tensions and politics affected narrators. Jackie Downer has reservations with groups that threaten to exclude others. Anya Souza is happy to no longer be part of a group. Groups have parallels with other friendship or work groups. Tensions are tied up with support. Furthermore, self-advocacy groups are not necessarily the central focus of narrators' lives. Phillip Collymore enjoys the freedom of having his own flat, sharing

it with his dog, coming back from the pub when he feels like it. Joyce Kershaw thrives on working in the coffee bar at the centre. They call it 'Joyce's café'. Jackie Downer has her religious faith, 'I can only believe in myself so much'.

Practical gains offered by self-advocacy groups

'I enjoy People First more than I did in the Day Centre because you do things all the time' (Lloyd Page).

According to Wolfensberger (1972), an integral part of normalisation is that community living serves both practical and emotional needs of people with learning difficulties, by promoting a 'valued role' (hence the more recent term of 'social role valorisation', Brown and Smith 1992a, b). In addition to emotional (expressive) gains cited in the above section, groups have served a number of practical (instrumental) needs of narrators. The life stories highlight narrators pro-actively taking up valued positions within and outside of groups. Here they used the opportunities offered by groups and developed their own self-advocacy (see Brooks 1991). As Lloyd Page says, *People First* gave him a sense of purpose:

'Get up, get washed, dressed, listen to some music in the morning, go to work as normal - do what you gotta do and that's it'.

Later, the group offered Lloyd grander opportunities, like working with the Open University, meeting the Minister for the disabled ('stupid man'!) and going to Canada. These opportunities may build on family ties:

'To get me over to Canada my mother and about four of her friends fund-raised for four years. They got £4,300 and that meant we could send four self-advocates and one supporter to Canada' (Lloyd Page).

Anya Souza appeared in a documentary on the TV. Joyce Kershaw was contacted through the self-advocacy network to take part in some research (my story). Jackie Downer has 'learnt a lot from so many people and done things that I'd never dreamed about'. Phillip Collymore feels he is 'coming on'. Four narrators have worked for self-advocacy groups on a regular voluntary basis.

After institutionalisation the acquisition of a job or other valued role can restore adaptability, self-respect and independence (Edgerton 1967, Edgerton and Bercovici 1976, Abraham 1989). Following Brandon and Towe (1989 see p20), Bhavnani (1990) and Sparkes (1994), self-advocacy may allow another way of conceptualising empowerment that is less paternalistic in nature:

'By speaking to other people in the group it gives you the confidence to speak to other people ... self-advocacy means that people with learning difficulties have a right to speak up for themselves. To see how they can express themselves in ways that people, members of the general public, can understand' (Lloyd Page).

Narrators conceptualised 'self-advocacy' in ways that contrast with literature that considers self-advocacy as something that people with learning difficulties are trained to do (for example Sievert, Cuvo and Davis

1988). Anecdotes are offered of self-empowerment rather than normalisation (see Mesibov 1976).

Self-advocacy groups as a context for self-definition

'Can I speak now? You should see what I've got - I've got two arms and two legs, I'm not physically handicapped actually' (Anya Souza).

The life stories pick up on the self-defining aspect of group membership. Vincent (1998) uncovered similar opportunities for self-definition, or what she calls the making of alternative frameworks of sense, in African Caribbean parents groups. Definitions have been a key component of the self-organisation of disabled people, like the UPIAS (1976) document that separated definitions of impairment and disability:

'Transforming personal and social consciousness is one of the key factors that separates new social movements from the old, more traditional social movements' (Campbell and Oliver 1996, p105).

Groups provide a context for re-evaluating old terms and coming up with new ones. This may be useful in view of the anxieties that parents face in explaining the label of learning difficulties to their children (Todd and Shearn 1997). Narrators prefer the more dignified term of 'learning difficulties' – reflecting the *People First* organisation's chosen terminology:

'We are people with learning difficulties, not what people used to call us, I won't say the word' (Joyce Kershaw – her story).

'Learning difficulties is more dignified' (Jackie Downer).

'Mental impairment? Now what the hell's that? Never heard of it. I've heard of learning disability. I think mental handicap is still being used but they shouldn't' (Phillip Collymore).

The term 'learning difficulties' infers that people want to learn and recognises that all people have some learning difficulty one way or another:

'A man couldn't do woman's work ... I said, "You want to come and see some of them working in the centre and I bet they'd have to teach you how to do it". Come and try and do our work and you'll soon find out if you've got a learning difficulty or not' (Joyce Kershaw – my story):

'I may need help in some things, but I'm not retarded. I can take care of myself ... Everyone needs help. Some people need more. Even the ones in the outside – the normal people, have marriage counsellors and other people to help them' (Martin Levine, a Canadian self-advocate, quoted in Friedman-Lambert 1987, p15).

Having knowledge about the label of learning difficulties provides people with self-understandings that can be applied in every-day life (Roffman, Herzog and Wershba-Gershon 1994):

'Who has 47 cells? I have. They haven't they've only got 46' (Anya Souza).

Narrators recognise how labels prescribe 'difference' through the values that are attached to them. However, having 'learning difficulties' does not mean that it has to be associated with 'handicap':

> 'It's good to use so that everyone can recognise the term' (Anya Souza).

Moreover, in line with other disabled commentators (Hevey 1992, Barnes 1993), media representations are of people with learning difficulties are pinpointed and challenged, including characters in popular television series, soap operas, documentaries and newspapers:

> 'This woman had put in the local paper, "Mentally handicapped are simple and happy people". I read it and thought the cheeky so-and-so' (Joyce Kershaw – my story).

Likewise, charities that play on people's pity as they fund-raise for 'the handicapped' are criticised - like 'MENCRAP'- as Jackie Downer puts it. In addition, opinions expressed in the stories highlight the various ways in which labels are internalised. Jackie Downer separates herself from 'less able' people with learning difficulties:

> 'I'm lucky I'm not like people with severe learning difficulties'.

Anya Souza dismisses the label:

'Would I say I have difficulties learning? No, I learnt well enough. I picked up things very quickly'.

Joyce Kershaw contrasts having learning difficulties with physical impairment:

'Learning disabilities' - I don't like that, disability makes you believe that we are in wheel chairs and we can't do anything for ourselves, when we can. We've got jobs now, we've got paid jobs' (my story).

Joyce's comments have parallels with those of a self-advocate cited in Sutcliffe and Simons (1993, p24):

'If you go for a job and you've got the label 'disabled' they won't give you a chance'.

The suggestion that people with learning difficulties are not 'as handicapped' as physically impaired people, is controversial. Nevertheless, it provides an interesting mirror image of prejudice expressed by some in the wider disability movement:

'I have to keep proving I'm not mentally disabled' (Elsa in Campling 1981, p85).

As Simone Aspis of London *People First* candidly writes:

'People with learning difficulties face discrimination in the disability movement. People without learning difficulties use the medical

model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as disabled people without learning difficulties. We want concentration on our access needs in the mainstream disability movement' (Quoted in Campbell and Oliver 1996, p97).

Some readers could suggest that narrators are hiding or minimising their impairments (Barnes 1996b). Another interpretation is that self-advocacy groups remind members of what they can do as opposed to what they can't do - what Booth and Booth (1994) call taking the 'capacity perspective' over the 'deficiency perspective':

'It could be argued that whilst the disability movement has fought the colonisers of disability (e.g. the medical and allied professions) for the right to define disability on their own terms, the fight against the colonisers of learning difficulty is of a different order; it is a fight against the denial of humanity itself; hence, this group' insistence on being perceived as *people first'* (Gillman, Swain and Heyman 1997, p690, italics in original).

Perhaps labels are unnecessary shorthand:

'You can't say you're 'just handicapped' because you're labelling someone and that's not the way to talk to someone' (Anya Souza).

In the long run dropping labels altogether may be better, 'I'm just me' (Jackie Downer), 'We're men and women' (Phillip Collymore). The

personal and political aspects of self-advocacy are highlighted in the ways in which narrators have considered the labels they were given.

Reflections on the early self-advocacy days

That's why they wanted me out of the house, because I started telling the staff what to do. I didn't do it before - I learnt it off *People First*. I took my ideas from here up to the house where I lived and said, 'Hold on, we pay you. If you don't like it you know where the door is' (Phillip Collymore).

Narrators came to groups often late in life from a variety of contexts. Past experiences affected how narrators experienced early days with groups. It is easy to understand the significance of *People First* for Phillip Collymore in view of his experiences in hospitals. However, Phillip, like other narrators, has other arenas of life that were just as important as the group. As with all friendship and work groups, tensions exist that may become too much, as they did for Anya Souza. Life stories point to the potential of groups to at least build upon past experiences of resistance, provide additional outlets for self-advocacy and add to the richness of lives. Moreover, taken for granted ideas like choice, independence and having a voice, are given a material base and context for enactment.

(3) Learning from experience - expert advice on self-advocacy

The life stories are interspersed with narrators' opinions about the doing of self-advocacy. Four themes are presented below: supporting groups, views

on the movement, the self-help and political nature of self-advocacy, and the future.

Supporting self-advocacy groups

Narrators have lived through the 'learning difficulties experience' of diagnosis, assessment, classification, surveillance, institutionalisation and training. Such experiences may breed awareness of good and bad practice. Add to that the vast experience narrators have had of self-advocacy groups and some informed understandings of support are articulated. To consider support, narrators were asked for their views on the role of advisors in self-advocacy groups. Narrators said they preferred independent advisors who work only for members, thus supporting previous literature on the 'independent advisor' (see for examples, Hanna 1978, Williams 1982, Williams and Shoultz 1982, McKenna 1986, Worrel 1987, 1988, Crawley 1990, Flynn and Ward 1991, Simons 1992, Downer and Ferns 1993, Sutcliffe and Simons 1993, Hampson 1994, Dowson and Whittaker 1993, Shoultz 1997a, 1997b, 1997c):

> 'The group is for people with learning difficulties, not the advisors' (Joyce Kershaw, my story).

> 'People should say "hold on we don't want a member of staff as advisor because we can't say what we want to and we can't say a lot. We want an outsider to come in to the group". I would go along with saying get an outsider, not a friend but someone off the street' (Phillip Collymore).

Furthermore, paying independent advisors may be fruitful, for then:

> 'We've got every right to tell the support worker what we think. That's the best way. We're the ones paying the staff and if the staff cannot handle it, well they know where the gate is' (Phillip Collymore).

Other narrators are not so sure, 'Paid workers create problems' (Jackie Downer). Narrators have little time for staff advisors - backing up previous negative appraisals of the staff advisor (see for example Hanna 1978, Worrel 1987, 1988, Clare 1990):

> 'I think there's a problem with advisors who are staff because you see them every day ... She was always watching you' (Joyce Kershaw – my story).

Yet life stories cite episodes of conflict between narrators and all types of advisor - taking understandings of support beyond the independent-staff dichotomy. An over-arching theme was the power that any advisor can hold (Worrel 1988, p35):

> 'Some can be a bit pushy and some can be a bit bossy... we're telling them what to do. Now some of the members don't do that yet but they're getting there' (Phillip Collymore).

> 'Workers can spoil members by being too caring. Be careful about caring' (Jackie Downer).

Joyce Kershaw, for example, felt that she was fighting a lonely battle against an advisor:

> 'I told the advisor, "You've frightened them all into putting their hands up. You frighten them into it instead of explaining, you just to take it all on your own. The group isn't for you, this is for people with learning difficulties ... it's for what we can do"' (my story).

Life stories highlight the complexities of support offered by advisors. Jackie Downer has worked as an advisor herself and has felt the tensions in pushing people a bit too far:

> 'I've got more power, I've got to be careful, I'm their own worst enemy sometimes'.

Narrators' experiences suggest that the power of advisors may be located within a number of roles and interactions rather than simply being a reflection of independent or staff status:

> 'The more independent you are the more free you are but it really depends on the advisor' (Jackie Downer).

As Chapter 5 pointed out, the label of 'staff advisor' may hide the various roles and positions taken by the advisor in the group. Also, to assume that such a label is synonymous with limiting support forgets narrators' reflections on 'good staff'. As Jackie Downer puts it:

'Some professionals are... professionals. Others are ace - they know where users are coming from'.

While advisors are important, 'We need them for everywhere we go' (Lloyd Page), life stories emphasise the self-empowerment of narrators in addition to the support that is offered by others.

Views on the self-advocacy movement

'The problem with that lot was that they'd never had a Down's Syndrome baby. 'Normal people' were in the association, I was the only one with Down's Syndrome working in that office for 10 years' (Anya Souza).

Narrators were asked for their views about the self-advocacy movement. They were outspoken in their analysis of recent and current developments. However, the interviews and the subsequent life stories tended to focus on each narrator's achievements and setbacks rather than wider issues such as disability movements. This personalised bent to the interviews and narratives may explain why the movement is not held up as a significant factor in the lives of self-advocates, as Jackie Downer puts it, you have to be yourself in the so-called movement anyway. Nevertheless, while questions still remain about the relative significance of the movement to groups and individuals, a number of opinions were expressed.

First, narrators assert that people with learning difficulties should lead the movement, for then, 'They'd get more people helping them' (Joyce Kershaw - my story). Second, dangers were perceived in the movement

becoming advisor-led. Self-advocacy is the in-thing now and open to abuse (Jackie Downer). For example, both Joyce Kershaw and Jackie Downer worry that advisors are taking over the setting up and running of England *People First*. A recent article by Lloyd Page and Simone Aspis (1997) takes up this point. They suggest that self-advocacy in the UK has become a professional industry for staff, service providers and researchers rather than a political collective for people with learning difficulties. Third, the movement's lack of financial support and the implications of these lacking resources were identified. Jackie notes the discrepancy in some groups getting 'mega-bucks' and others getting little. This point also concerns Lloyd Page who suggests that there is a need to weigh up the balance between England *People First* and other groups. Fourth, a number of anecdotes support seeing the *People First* movement as a social movement:

'It's a network of people supporting one another' (Jackie Downer).

'I've seen *People First* grow in ten years, It's grown for the better' (Lloyd Page).

Some of the experiences of resistance recalled by narrators have resonances with Marx and McAdam's (1994, p3) definition of social movements as:

'Organised efforts to promote or resist change in society that rely, at least in part, on non-institutionalised forms of political action'.

Jackie suggests that unity is important – a point often made by physically impaired activists in the disability movement (Stuart 1993, Morris 1996, Shakespeare and Watson 1997). The similarity of experiences expressed in

the five life stories in this thesis highlight shared ground that can be used as a starting point for unity in self-advocacy groups: collective identity as a base of self-empowerment and organisation (Oliver 1996).

The self-help and political nature of self-advocacy

'I thought who are you? It takes time to get married, it's a big step to go through in life. Things can wait. I'm young, I'm 34 and I'm single. I have my independence. It might affect my benefits' (Anya Souza).

In describing self-advocacy inside groups, stories are told of travelling the world, speaking at conferences, having words published and carrying out research. There are anecdotes of appearances on TV and radio, the lobbying of MPs, involvement at user consultation meetings and the starting up of self-advocacy groups. These achievements appear even more remarkable alongside tales of cries for help in various institutions, sexual and physical abuse and separation from family members. Many of these experiences may be alien to readers but they will also identify similarities. Like the anxieties of going to school, leaving and getting a job, the importance and difficulties of relationships, and hopes for the future. Self-advocacy is described in personal and political terms:

'It's both these things ... It's personal, there's no wrongs or rights' (Jackie Downer).

'We're just ordinary people with learning difficulties' (Lloyd Page).

Self-advocacy is presented in terms of personal gains, like making friends:

'With that I'm starting to go out in the evenings, and go to the pubs and clubs and make friends that way' (Phillip Collymore).

'Me and my friends go into the bus station cafe for a drink. We pay in turns' (Joyce Kershaw, her story).

Indeed, these qualities come with tensions. Anya Souza left *People First* because of various squabbles, 'I was being the star and they hated it', and Lloyd Page has noted others' envy, 'Aye, aye, that'll get you nowhere'. Narrators do not rely solely on groups for personal and political benefits. While groups may provide a safe context for taking a few safe steps towards independence, narrators recognise that life goes on outside:

'I have to do things on my own because my mother's not there' (Anya Souza).

The political aspects of self-advocacy permeate the narratives from an informal incident like asking for tea not coffee (see Jackie Downer), through to formal user consultation meetings, where people should learn to talk properly (as argued by Joyce Kershaw, both stories, Phillip Collymore, along with Sutcliffe 1990, p28, Wertheimer 1990). Self-advocacy emerges as something materially and actively understood in the anecdotes told by narrators. Groups appear to provide a context in which the personal and political are voiced and acted out.

Reflections on doing self-advocacy - and so to the future

'I could tell you about the past, the future in 15 years time, how I'm going to cope, will I cope' (Phillip Collymore).

In reflecting on the past, narrators see a bright future. Joyce Kershaw hopes that her efforts will be of use to young people with learning difficulties (both stories). Lloyd Page thinks that self-advocates have got the power to do what they want:

'Self-advocacy is looking good - more stronger'.

Jackie Downer reckons the movement is going from strength to strength:

'The picture is good, but it's happening more in some places than others'.

Consequently, there is still a lot of work ahead for self-advocates and groups - to build a foundation for younger members for the future (Phillip Collymore). This includes publicising the concerns of self-advocates (see Walmsley 1992) and hopes for a 'new world' (see also Finkelstein and Stuart 1996):

'You've got to keep reminding people - especially on the outside, you've got to remind them all the time that we are different to what they are, which, fair enough, we are. We've all got our own ways of living' (Phillip Collymore).

Narrators' recognise the complexities of support, self-advocacy as a movement and the personal, political characters of being a self-advocate.

(4) Reflections - Life stories, the self-advocacy group and resilience

The analysis thus far has examined the emergence of narrators' resilience in and outside of the self-advocacy group and presented a number of pointers about doing self-advocacy. This final section draws together more general conclusions. Two themes are presented: the storied nature of self-advocacy and relevance of these stories to other self-advocates.

The storied nature of self-advocacy

'One person I met was Pat Worth - it was great because you listen to his life story and it's brilliant' (Lloyd Page).

Cohler (1991) asserts that life stories are a useful medium for documenting responses to adversity. Narrators often present stories in ways that accent resilience over adversity - so as to maintain a sense of coherence and personal integrity across the period of life that is being told. Consequently, narrators tend to recount past experiences in ways that emphasise their activity, intention and direction. This may be the case particularly for narrators who readily agree to tell their accounts and so have stories that they want to publicise. However, these incidents of bias may not be a bad thing when the narrators are from a marginalised group. Too often people with learning difficulties are submerged under the system, the therapeutic technique or the goals of the sponsored programme (Heckel 1968). By

contrast, their life stories can highlight the other sides to life that are often ignored by dominant institutions and practices (Gillman, Swain and Heyman 1997).

The five life stories in this thesis can be seen as examples of a different narrative type to the 'problem saturated' descriptions offered by case histories and other formal documents (Ibid., p689). Their accounts introduce the idea that narrators do have influence over and become active in their own lives. In this sense they are counter or alternative documents that contribute to a revision of official learning difficulties documentation:

> 'People with learning difficulties might form a 'resistance movement' – perhaps through the already well established self-advocacy movement – in which the subjugated voices of people with learning difficulties can be heard in the telling and 're-authoring' of their own stories' (Ibid., p689).

These stories present another side of self-advocacy to previous literature that has been concerned with generalisations, organisational typologies and the role of advisors. The five narratives highlight the everyday nature of resilience in spite of the oppressive conditions outside of self-advocacy groups and present tales that give meaning to the term 'self-advocacy'. Formal and informal, low and high-level, individual and group, private and public aspects of self-advocacy are articulated. Even people with learning difficulties can lead busy and varied lives. Moreover, the life stories challenge accounts of people with learning difficulties that view behaviour in terms of an oversimplified linear relationship between some ill-defined (and ever-changing) state of 'retardation' as cause and retarded behaviour as

effect (Levine and Langness 1986, p192). Life stories remind us that people with learning difficulties are not helpless, involuntary victims of genetic adversity, or the degenerated shells of individuals who 'might have been' (Whittemore, Langness and Koegel 1986, p5).

Self-advocacy as resilience, an inclusive social model of disability and the relevance of the stories to other self-advocates

'I was awful quiet and they all shut up and listened' (Phillip Collymore).

Resilience is a recurring theme throughout the life stories. Perhaps self-advocacy can be defined as, the public recognition of people with learning difficulties' resilience. For Bogdan and Taylor (1982, p52) a strength of life stories is that they force readers to think of narrators as people so that categories of all kind become less relevant. In this sense, resilience is typical to any life account, particularly for those who have survived 'the learning difficulties experience'. As Atkinson (1993, piv) observed about the people involved in her oral history project:

'They do not emerge in their accounts as victims, but as people who survived, and often defied, the worst aspects of the system'.

To pinpoint when narrators were involved in self-advocacy illuminates their larger narratives. Their stories show that 'self-advocacy' is not necessarily given to or learnt by people with learning difficulties in self-advocacy groups, but exists in a variety of contexts. However, the experiences that are documented are those of high-fliers in the movement:

'This is my experience. Every experience is totally different and you need to go back and ask self-advocates' (Jackie Downer).

Perhaps, narrators' past experiences of adversity and opportunity have made them into the resilient characters that they are today. Nevertheless, their stories have wider links with people with learning difficulties generally. In terms of supporting self-advocates, these stories have highlighted that self-advocacy already exists prior to joining a group. Supporters could bear this prior self-advocacy in mind. Stories also illustrate how structures impact adversely on lives, though resistance does occur and self-advocacy groups can enhance resistance. These accounts are historical documents of a past epoch of exclusion. However, their contemporary relevance remains, in light of recent policy changes in Britain and elsewhere that reinforce segregation and re-categorise an individual model of disability (Persson 1998, Potts 1998). Finally these life stories highlight the relevance of a social model of disability to people with learning difficulties – that self-determination flows within people who have suffered the indignities of discrimination.

Conclusion

This chapter has considered the relationship between self-advocacy, self-advocacy groups and some of the life experiences of narrators. Against a background of structures that threaten to deny communication, the human drive of people with learning difficulties to communicate is presented. The will to move on and achieve independence is articulated while barriers that create dependence are recognised. Moreover, the capacity to rebuild

shattered lives and the power of self-advocacy, with others' support, are illustrated. In this chapter I have drawn upon these life stories in order to examine the lived impact of self-advocacy. In the next chapter I will consider the stages of collaborative narrative inquiry that created the five narratives.

Chapter 8

Stories about writing stories

Introduction

'Whether talking about disability or any other topic of social science, surely reporting research and telling stories are two very different activities. We beg to differ ... the goals of research are perfectly compatible with the discovery of good stories' (Ferguson, Ferguson and Taylor 1992b, p1).

In this chapter a research story is told to account for the stages of collaborative narrative inquiry that created the five life stories in this thesis. In part one of the research story, a number of issues will be considered in relation to interviewing people with learning difficulties. Part two introduces writing techniques that were used to illustrate how spoken words (interview material) were turned into written text (stories). Part three illustrates how narrators became writers and critically considers the relationship between narrative inquiry and 'empowering' disability research. The story ends with a tale of a research relationship that looks closer at the collaborative nature of life story research. This chapter builds upon previous papers (Goodley 1996a, 1996b, 1996d, 1997b, 1997c, in press, b).

Part 1 of the story - Interviewing top 'self-advocates'

This research story opens with the collection of experiences, views and opinions of narrators in interview settings.

General style of interviewing and telling stories

Lofland (1971) asserts that the format and content of interviews should at all times follow the issues of significance identified by narrators. In contrast, Tremblay (1959) argues that interviewers have interests that they will want to explore in the interview. I had some questions to ask (*Appendix 3, 2*), but they were used mainly as reminders and were not needed as central themes around which to organise dialogue. All narrators spoke openly, gave extended anecdotes, reflected on past experiences and considered present situations. Interviews consisted of, 'a friendly and informal atmosphere and a conversational format' (Atkinson 1989, p70 in Brechin and Walmsley). However, narrators did not just tell stories. Their reflections on past and present experiences were tangled up in opinions and views, which had implications later in the writing up of the interview material into life stories.

Over-enthusiastic interviewing

For Taylor and Bogdan (1984, p77, pp94-96) the interviewer, not the interview protocol, is the research tool. Interviewers should continuously appraise the interview situation by opposing sterility, being non-judgmental, letting people talk and sensitively probing. Lloyd Page was the first to be

interviewed and became the unfortunate recipient of over-enthusiastic questioning.

Lowe and de Paiva (1988) have highlighted the 'tendency' for narrators with learning difficulties to reply with simple yes or no answers. Atkinson (1988, 1993) found that frequently asked questions emphasised the researcher's interests and helped to build up trust and rapport. O'Donnell (1976), Flynn (1986), Flynn and Saleem (1986) used direct questions to ascertain the views of people with learning difficulties. Perhaps literature was either misunderstood or taken too literally into the interview with Lloyd Page. I was impatient, fired quick questions and gave him little time to respond. He said afterwards that he felt, 'Grilled like a tomato'. Field notes, written after the interview, reflect on my failings:

'Some of the literature suggests that snappy, quick questions 'work best' and perhaps I had gone into the interview with such preconceptions. This assumes all interviewees with learning difficulties are the same - they're not!'

In contrast to Shakespeare (1993a), who felt that she had acted too naturally in her interviews, Lloyd Page's interview highlighted problems with literature-based interviewer posturing. Viewing Lloyd as a person with learning difficulties, who would respond best to a particular type of questioning, assumes that people with learning difficulties are an homogenous group and unquestionably translates 'text-book' guidelines into the interviews (see Lawthom 1996). Good narrators are rarely found, rather they emerge in the course of one's everyday activities, not in

artificially contrived research contexts (Taylor and Bogdan 1984, pp86, Edgerton 1984, Swain 1995, p86).

The pros and cons of 'natural' interviews

The four narrators interviewed after Lloyd were approached in a more 'natural' way. I tried to strike up conversations in the same way that I would with peers when I really want to hear their opinions! Interview transcriptions revealed many leading questions. Some literature that deals with drawing information from people with learning difficulties suggests that leading questions are inappropriate. The reasoning behind this claim is the reported tendency of people so-labelled to respond affirmatively to questions regardless of their content (Sigelman, Schoenrock, Spanhel, Hromas, Winer, Budd and Martin 1980, Sigelman, Budd, Spanhel and Schoenrock 1981, Sigelman, Budd, Winer, Schoenrock and Martin 1982, also for general points see Orne 1962).

Simons (1994) and Booth and Booth (1994) argue that assuming acquiescence on the part of people with learning difficulties unquestionably presumes deficit. When people acquiesce, perhaps this is because they feel powerless. Maybe the narrators in this study felt in control: a testimony to their involvement in self-advocacy. Leading questions or 'probing' are a necessary part of the exchange of information between two people (Taylor and Bogdan 1984, p98). In this sense, Oakley (1981, p58) suggests that acting as 'naturally' as possible in interviews is a condition under which people come to know each other. The better the chat the more leading the questions (Tremblay 1959). Furthermore, the five narrators in this study did not simply acquiesce. Joyce Kershaw ignored or spoke over some of my

queries. Anya Souza presented long anecdotes that kept questions to a minimum. Phillip Collymore queried questions, 'Say that again', and asked me to say a word that he couldn't, 'Vulnerable? That's right - that's the word'. Lloyd Page had obviously got sick of my grilling and stopped the interview by turning on the TV.

Anecdotes and opinions of narrators were responded to in a value-laden way. Hopefully, this made clear my interest in what narrators had to say (see Masson 1990, Atkinson 1993b). Nevertheless, acting naturally has implications. Narrators' words were often reactions to my leading questions and value-laden responses. These 'natural exchanges' were used in constructing narrative. Consequently, my words may have unnecessarily littered the interview material that was later used for writing stories. With hindsight I could have balanced reacting to disclosures by keeping my opinions to myself.

The presence of others

Unplanned situations occurred with Lloyd Page and Phillip Collymore. At their interviews other people who were present, affecting how their experiences were disclosed. Interviews can benefit from the presence of others (Walmsley 1995), though interviewees may not. Lloyd Page's mother gave her opinions and reminiscences. At other times she corrected and disagreed with Lloyd. I felt tense in the interview, anxious that she was talking over Lloyd. I felt less concerned on transcribing the interviews. Her words only appeared a few times and appeared inconsequential beside the many passages of text provided by Lloyd.

I was less anxious in Phillip Collymore's interview, even though one of his supporters was present throughout. The supporter sat in the office drawing up a poster and only spoke when Phillip threw a comment her way, 'Do you know we haven't got the beds in our house yet', 'Haven't you?' (supporter); asked her questions, 'What's that woman's name?', 'What's that word I'm thinking of?', 'Where's that place we went to last week?', or when Phillip was down on himself, 'I'm getting there slowly', supporter, 'You're doing a great job'. Phillip used the supporter as a resource. Perhaps Lloyd Page also appreciated his mother being present and I was the one with the anxieties. However, her attendance at the interviews, like my dominant voice, inevitably led to dilemmas when Lloyd's life story was written (see below)

Delving into lives - personal documents, taped and written notes

According to Tremblay (1959, p60), a good interview encounter develops the narrator's skills to recall facts and situations, stimulates memory and facilitates the expression of recollections. Familiar documents and environments appeared to enhance the disclosure of stories. Anya Souza showed me around her house, pointed to pictures of her family and her latest stained glass collection. Joyce Kershaw lent me a book in which she had co-written a chapter. We walked around her flat, she directed me to the war memorabilia that her brother had emblazoned across the walls. Coffee was made. The dining table cleared. Lloyd Page brought down various leaflets from his bedroom. He showed me a pot racoon given to him and other delegates at the 1993 International *People First* conference. Jackie Downer and I sat at her usual table in the restaurant. She broke off from the interview to talk to the waitress. Phillip Collymore turned up late after lying in bed. We skirted over the posters presented on the walls of his office. He

pointed out pictures of peers at conferences and coffee cups with daft designs.

Photos, pictures, personal memorabilia and possessions exist as productive resources for discussion (Plummer 1983, Taylor and Bogdan 1984, pp91, March 1992, Minkes, Robinson and Weston 1994, Swain 1995, p86). Familiarity can promote informality. By contrast, tape-recording may have emphasised the esoteric nature of research (Booth and Booth 1994, Walmsley 1995). Lloyd Page appeared to be uncomfortable when the tape recorder was placed before him. I stopped it many times. Other narrators did not seem so phased. Written notes were taken with Jackie Downer because the tape-recorder was not working. Writing down what was said appeared to enforce some structure on conversations. Jackie took the opportunity to re-phrase things she had said, to give more precise and thought-out reactions, and to indicate links with experiences that had been written down earlier. In addition, she stopped me a couple of times from writing down what she had said, asking me to re-phrase it or simply not include it in my notes.

Reflecting on part 1 of the research story

I initially went into the interview with Lloyd Page assuming that he, and 'others like him', would be vulnerable and that interviews would be problematic. Lloyd helped me to re-appraise these assumptions but perhaps I acted too naturally in subsequent interviews. Another point emerged with respect to the storying of experiences. While narrators told stories, their disclosures were not always storied. Opinions were interjected alongside anecdotes. The next section considers how these anecdotes and opinions were written up as life stories.

Part 2 of the story - Writing life stories alone

'If we wish to hear respondents' stories then we must invite them into our work, as collaborators, sharing control with them, so that together we try to understand what their stories are about' (Mischler 1986, p249).

Writing stories, asking questions

Little has been written about the writing of life stories (Plummer 1983, Hatch and Wisniewski 1995). In collaborative life story research the final draft of a life story is the narrative of both narrator and writer (Ferguson, Ferguson and Taylor 1992c, p299). Plummer (1983, p111) encourages life story researchers to:

'Get your subjects words, come to really grasp them from the inside and then turn it yourself into a structured and coherent statement that uses the subjects words in places and the social scientist's in others but does not lose their *authentic* meaning' [My italics].

Two questions can be posed to explore the position of narrator and writer in collaborative narrative inquiry. First, how does the writer construct the life story of the narrator? Second, to what extent do narrators become involved in the writing of their own life story?

The first question resonates with Dexter's (1956, p10) demands for 'a sociology of those who study mental deficiency'. As Atkinson (1993b, p58) notes:

'There is, however, more to telling - and hearing - people's accounts of their lives and experiences than simply providing a forum. The role of the researcher, or listener, has a bearing on how stories unfold and what they are about'.

Researchers have spent little time examining how they move from what they collect (e.g. interview transcripts) to what they tell (e.g. stories) (Plummer 1983). More time is spent considering how information is collected (Walker 1981, p157). Therefore, examining the hand of the researcher in the writing of stories would appear to constitute a useful exercise.

The second question presented above, takes on a particular slant in the case of life stories which are the creation of two minds working together (Whittemore et al 1986, p6, Sarbin and Kitsuse 1994, p8). Bertaux-Wiame (1981, pp264) argues that social investigation is not a matter reserved for researchers. Accordingly, how can narrators become involved in the social investigation of writing their life stories?

Below, I will consider how the narrators and I wrote the five life stories. A number of textual strategies will be presented. These strategies were employed to show 'who the words belonged to' (mine, the narrators, others present at the interview and afterwards, secondary material) and were originally used on writing the *annotated versions* of the life stories.

Appendix 3, 3 presents extracts from each narrator's annotated narrative, illustrating these textual strategies. In addition, some of the decisions (by narrators and I) that affected the writing process will be discussed. How and why certain material and words were included and excluded from the first and final drafts of the life stories will be considered. Therefore, some aspects of the research relationships that led to the finished narratives will be referred to[1]. The research relationship with Joyce Kershaw stood out and is documented in detail later in this chapter in *'Part 4 of the story'*.

The relationships that led to the finished narratives

Narrators were sent drafts of their life stories, double-spaced, with a large clear font (Arial 16) and without annotations. Briefly, the stages of narrative inquiry for each narrator were as follows:

Lloyd Page – Lloyd and his mother made changes to the first draft. Together they re-wrote a paragraph, typed up the changes and sent them back. The second and final draft was written and accepted.

Jackie Downer – Jackie reviewed the first draft alone. Changes were discussed and made during a telephone conversation producing the second and final draft.

Anya Souza – Anya and I talked on the telephone about how to include a potentially libellous passage in her account. The first draft was then written

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[1] see *Appendix 3, 7* for detailed accounts of relationships and *Appendix 3,4* for related correspondence.

and Anya wrote down various changes before sending it back. The second draft was written up, sent back and accepted.

Phillip Collymore – Some weeks after the interview, Phillip and I spoke on the phone about including his experiences of sexual abuse in his story. He remained as certain as he had been at the first meeting, 'I want people to know'. Written and audiotaped versions of the first draft were sent as requested. Then I received a phone call from the police. They were investigating Phillip's claims about the abuse. As he was a key witness they were concerned that his story might be leaked. I phoned Phillip to tell him what the police had said, although he already knew they were going to approach me, and he agreed that they could see his life story[2]. Police and a social worker visited me, read the story and asked for a statement about the interview. Speaking with Phillip afterwards, he was adamant that his experiences were included in my thesis, so asked that his name and the names of the staff were changed. The final draft was sent on to Phillip[3].

Writing the first drafts - including and excluding words

Turning interview transcriptions into stories is a difficult process. Writers face problems of contamination: first, when moving from the animated spoken word to the 'frozen text' (Sparkes 1994, Fairclough 1992, p229), and second, when turning disclosures into stories (Plummer 1983, 1995).

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[2] Legally the police could have demanded to see the story even without Phillip's consent but they allowed me to follow through the ethical procedures that I had outlined at the start.

[3] At the time of writing I have been told that I may be called as a supporting witness to Phillip and the life story might be used in court.

Consequently, a number of textual strategies were used to highlight how spoken words (from the transcriptions) were turned into written texts (in the life stories).

For Plummer (1983), how and why words are included in stories needs to be acknowledged. To include some words and exclude others may be seen as 'distorting the information people give'[4]. However, any type of qualitative analysis distorts the information received. Thematic analysis, for example, is especially harsh in the way it takes, bit by bit, from the experiences told by narrators. Similarly, decisions behind the writing of stories are arbitrary, open to personal preference and specific to a given time and place. However, writing annotated versions and highlighting some of the decisions, acknowledges some of the incidents of 'contamination'.

Including self-advocates' words - writing the spoken word and elisions

First drafts were created primarily from a review of the five transcribed interviews. Words of self-advocates were cut and pasted into the annotated narratives as unaltered text and page number of transcription:

'I was born in Hampstead in 1962 {1}'.

The same format was used for Jackie Downer's words, even though they were my written notes (including summarises, abbreviations and, in some cases, direct quotes).

Initially, attempts were made to fill life stories with a sense of the spoken word (see for examples, Tony Parker 1963, 1990, 1994, Potts and Fido 1991 and Booth and Booth 1994). Jackie Downer said, 'People with learning disability', as opposed to, 'People with learning disabilities', reflecting her accent. These were kept in. Anya Souza had a tendency to finish sentences with, 'Basically'. A few of these were added. However, Joyce Kershaw rejected these tactics when they were employed in the first draft of 'Danny's story' (see part 4 of the research story below). Consequently, less attention was paid to presenting the spoken word in the life stories of Anya Souza and Phillip Collymore.

Elisions of material from different parts of an interview enhance a narrative's flow, style and readability. For example, the paragraph below combines material from three different pages of the transcript:

'I've taken some photographs of all the hospitals that I visited {29}. [I give talks at Universities] {7} ... [because] professionals need to learn about us, they need to understand us {8}' (Lloyd Page).

Including my words - to summarise, for grammar and for meaning

All annotated narratives were filled with my words, presented [like so]. First, they were added to summarise anecdotes and to keep the narrative concise. Summarising started early on in Jackie Downer's interview through note taking. Second, my words were added to correct, syntax and grammar. For example:

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[4] A qualitative research psychologist put this point to me at a seminar I presented (Goodley 1996c).

'[I gave a speech to] {2} over 300 people {13} - [it was] nerve-wracking {13}'.

Here, the written word is focused upon and spoken voice loses out. Third, words were added to the narrative to clarify meanings within stories:

'[I came back from the conference] {3} and [helped] set up [a] group {3}'.

'Helped' was added because Lloyd Page had spoken about setting up the group with others. Finally, my words were used to help the story along. Putting, 'So then', 'After that', 'The next day' and so on, aids narrative flow, provides elisions between anecdotes and starts or concludes sentences.

Including our words - questions and assertions and narrators answers and responses

Sometimes questions that I had asked that were verified in the interview were added to the narrative. For example: Danny, 'Do you think that's important?' Lloyd Page, 'Yes', became:

'[I think that's important] {7}'[5].

Leading questions were common, reflecting a conversational format: Danny, 'Why did you want to get into self-advocacy?' Lloyd Page, 'Because it's a good thing to do', became:

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[5] Similarly for Jackie Downer, when she verified the written questions in my notes, these were included as [question] and {page number of notes}.

'[Why did I want to get into self-advocacy?] {5} Because it's a good thing to do {5}'.

There are many leading questions and short answers in Lloyd Page's annotated narrative, corresponding with my impatient style. By contrast, other narrators were given more time to respond in interviews which led to more continuous prose in their transcriptions. A number of times, narrators responded to assertions that I made:

Danny: Yeah, let's be honest you're doing a lot more than perhaps other self-advocates are doing. There's not many self-advocates who could say they've been on the telly twice.
Lloyd: There's not many self-advocate people like me you know.

This became:

'[I've done lots of things - I suppose there's not many self-advocates who could say they've been on the television twice] {17}'.

My words were always going to be strong in the written narrative because of the conversational format of interviews. However, certain styles of questioning emerge in the narrative as if they were the words of the narrator.

Including others' words - aiding or stifling the words of self-advocates?

Lloyd Page's Mother's words ended up in his annotated narrative $||_{mum}$ like this $||_{mum}$.[6] Her obvious impact on Lloyd's life justifies including some of

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[6] The words of the supporter present at the interview were not added in Phillip Collymore's life story.

her words (see Chapter 6). However, when she once 'corrected' Lloyd this problematised the inclusion of her comments in the text:

> Danny: How do you find them [Doctors and nurses]?
> Lloyd: I must admit that I've got a bit of a negative view of Doctors, nurses and professionals.
> Danny: Why though?
> Lloyd: You see they don't listen to us.
> Mother: They're beginning to.
> Lloyd: They're beginning to listen us... what do we need?

In the narrative this became:

'I must admit that I've got a bit of a negative view of doctors, nurses and professionals. You see, they don't listen to us, [but] they're beginning to {8} listen - what do we need? {8}'.

All but one of the words in above passage came from Lloyd but his Mother's influence on what he said is not conveyed. Subtle relational interactions are lost on moving from animated interviews to written frozen texts (Sparkes 1994). Generally Lloyd's Mother stayed in the background (see *Appendix 3, 7*). At other times she was encouraging:

> Mother: He got the name changed.
> Lloyd: Yes from the local council.

This became:

'[I got the council to change the name] (from mental handicap to learning difficulties)' {9}.

Interviews with two or more people will result in discussion, disagreement and consultation. People tell the 'same story' in different ways (Bertaux-

Wiame 1981, pp259-260). A limitation of collaborative life story work is that the stories of one narrator can take second place to the stories of another narrator, and then third place to the narrative construction of the writer. However, though the words of others (including the writer) permeate the narrative, in some cases these words are directly authorised by narrators. For example, the longest paragraph of unaltered text in Lloyd Page's annotated narrative came from him reading out part of a leaflet explaining the 'Equal People' course.

Excluding words that do not help the narrative

Sometimes long discussions gave rise to material that did not, in my opinion, help the narrative. Words were omitted when they were *trivial* (for example, like the *exact* time a person got up for work. 'Early in the morning' would perhaps suffice); *repetitive* (when the same information was repeated later in the interview) and *too detailed* (giving pseudonyms to people who helped start the group - 'Two staff members' is ample information). Walker (1981) recognises that while interviewers are concerned with the accumulation of information, writers aim for simplicity and economy. However, cutting words loses personal significance that narrators attach to anecdotes.

Excluding words that work against primary narrators

Lloyd Page's Mother's presence at the interview prompted the formulation of some general rules - other narrators' words were excluded when they challenged, contradicted or spoke over the stories of the primary narrators. For example, Lloyd's Mother had spoken about what happens in self-

advocacy groups. Her account was not needed because Lloyd had offered his own. However, this rule was inconsistently applied (see above 'including others' words). The over-riding aim was to try and authentically capture some of the stories that narrators had told me.

Reflecting on Part 2 of the research story

Some general strategies emerge in the writing of life stories, though trying to write a good story ensures that the process resembles an unscientific study by an untrained observer of an insufficiently understood problem (Parker 1963). Consequently, my attempts to write good stories had to be checked by narrators.

Part 3 of the research story - Writing the final drafts - collaborative ventures

Each narrator reviewed the drafts and made changes and additions, which were presented in the annotated narratives as follows[7]:

- Changes and additions made during telephone conversations appeared ((($_{tel}$ like so))))$_{tel}$ in the annotated versions.

- Changes and additions as directed by narrators (either over phone or as written) appeared ///$_{dir}$ like so ///$_{dir}$.

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[7] see *Appendix 3, 3* for examples within selected texts.

- Changes and additions made after consulting narrators, e.g. changing spoken form, 'Owt' in first draft, to 'Anything', appeared \\\\\\con like so \\\\\\con.

- Paragraphs that have been moved are indicated by ◆ - where they were originally) to ◆new - their new position in the text.

Some of my editorial decisions were addressed.

Changing names, structure and tense and adding drama

Narrators re-assessed the structure of their narratives. They suggested that paragraphs were moved or taken out, tenses were changed from present to past, inverted commas were added to convey a sense of critical usage of a word (as in Anya Souza's piece, 'Respite care' and, 'Bereavement') and corrections were made. Narrators stepped into the writer's role in subtle ways. The seriousness of a situation was addressed, 'The custard thrown over me was, 'Boiling', not, 'Hot'' (Anya Souza). A sense of the drama of an event was relayed. My words were also discarded if they were unintelligible or factually inaccurate.

Re-evaluating old stories

Biographies are in a constant state of becoming (Turner 1991, pp232-233). Jackie Downer's thoughts on *England People First* had changed since our interview. We agreed to keep in her initial reservations but to show how her views had changed. Lloyd Page and his mother felt that a small paragraph of the narrative inferred 'sour grapes' on his part. They offered an

alternative account that was written up in place of the offending passage. Anya Souza felt that what was written about her mother telling her off was too forceful. We took out this passage and added another that was less emotive. Yesterday's stories were rewritten.

From private stories to public stories

Participants were reminded that their stories would become public. Four narrators kept their names to their stories. For Anya Souza, keeping her name meant that some libellous comments were taken out. In discussions (three phone calls in total), Anya felt that a certain passage could be seen as, 'Slandering the characters of a number of people', 'That's what they accused me of before, you know'. So what did we put down? She wanted to keep her name and acknowledged it was 'a difficult one'. Consequently, a general passage of prose was written that captured her feelings but lacked detail and didn't name names. Similarly, Jackie Downer did not want me to name a group that she had criticised. Instead she suggested inserting, 'Certain groups'. By contrast Phillip Collymore wanted to make public his experiences of abuse. He decided to follow the advice of police and change his name.

Reflecting on part 3 of the research story: Collaborative life story research - a case for empowering research?

A number of disabled researchers have called for empowering disability research (Abberley 1992, Oliver 1992, 1996, Morris 1996, Barnes and Mercer 1997). Central to the doing of empowering research is the notion of praxis. Lather (1986) and Oliver (1996), for example, assert that participants should be involved in assessing the method, analysis and the

effects of the research. This has parallels with Guba's (1993, piv) concept of the 'hermeneutic-dialectic' in praxis, where method and results are built upon and through one another. The end product of praxis is when research, 'empowers not only the researcher but also every individual in these contexts' (Erlandson et al 1993, pxviii).

In this study, collaborative narrative inquiry has some parallels with empowering disability research. At first, narrators disclosed experiences to a writer who became the storyteller. Then, when the first drafts were given back, narrators addressed how their experiences appeared as written stories. This method appears to make links with Lather's (1986) 'fundamental point' about empowering research: the promotion of self-reflection and deeper understanding of the research situation by the research subjects. Narrators participated in the formal presentation of their experiences.

However, whether or not the five narrators felt empowered by their involvement in the research is a difficult question to answer. Neither were their lives changed markedly by their involvement, nor were they consulted about the links made between their stories and wider issues (chapter 7)[8]. Perhaps collaborative life story research injects only one consideration into the empowering disability research paradigm. As Sparkes (1994, p180) puts it:

'There is a need for researchers to move beyond paternalistic notions of 'giving' voice, towards a view of life story as an expression of

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[8] Recent studies have attempted to consult people with learning difficulties in the stages of analysis (Mitchell 1997a, Mitchell 1998, and Stuart 1997). In the future I would hope to develop similar projects.

solidarity with those who share their stories in the hope of creating individual and societal change'.

Actually getting people with hidden lives into the research context may the first step of praxis-orientated research (Ferguson, Ferguson and Taylor 1992c, p299). Tapping into the common experience of storytelling allows a useful starting point when storytellers already exist. While all narrators took up the challenge of narrative inquiry, one narrator challenged the collaborative aspect of the research. This research relationship is documented in detail below and takes further the critical agenda with respect to 'giving voice'.

Part 4 of the research story - 'Give 'us a say, Joyce'! The tale of a research relationship in narrative inquiry

The research relationship formed with Joyce Kershaw shows how narrators can take up the challenge of narrative inquiry themselves. Most time was spent face to face with Joyce Kershaw out of the five research relationships. She is the only one with two stories in this thesis: one that I wrote (Danny's story in *Appendix 3, 5*) and the other that she wrote (Joyce's story in Chapter 6). As she put it:

> 'Do you know I'd been thinking about writing my story for years. It was you who made me do it - you got me so mad'.

Stages involved in the writing of the two stories constitute stories in their own right.

Writing Life story 1 - 'Danny's story' of Joyce (Appendix 3, 5)

The first attempt

The first draft was constructed using the textual strategies outlined above. As mentioned earlier, around the time of writing 'Danny's story', I was trying to write how narrators spoke. For Joyce, in went phrases such as, 'Oh they were', and, 'Yer knows'. Keeping with this personable style, in came lots of, 'I says ... and then he says...' and her accent was represented though the additions of 'Cause', 'Owt', and 'Summat' and so on. Writing was easy. Long passages of prose were cut from the transcript and pasted into the draft narrative. I thought I was letting Joyce speak to the reader as she had to me. Soon afterwards I phoned Joyce to tell her that I'd finished her life story, of my attempts to write how she spoke and the necessary name changes. She said she'd have a look at it.

A week later Joyce phoned me at home. She was not happy with the story. She wanted to meet up again to review it. At our next meeting I read aloud what I had written. As I read she was reminded of what she had told me. At times she would start retelling a story. I would interrupt to read from the part of the narrative, to show that I had got her anecdotes down on paper. However, Joyce remained unhappy about my writing style and asked for the first draft to be re-written. I thanked Joyce for spending so much time with me. 'That's all right, thank you for listening to me', she replied, 'but when you're writing my story Danny - use your imagination'.

Back to the drawing board

Joyce had identified a number of problems with the first draft. My attempts to have her talking to the reader through the narrative had failed. 'It's difficult to read', she told me:

> 'When you were asking me questions and I was answering them, I would say, "Then he says and I says", but that was then - we were talking. I didn't realise I spoke like that!'

In the second draft 'owt' became 'anything', 'summat' became 'something' and so on. There were also a few occasions in the text when Joyce felt that I had not quite conveyed the significance of some of her experiences. For example, to the part of the text that refers to Joyce's confrontation with a journalist, she asked that I add:

> 'After a few times of me asking and her refusing to tell me I followed her down the steps and I said, "Excuse me, but do you think it's right?"'

Over the next two weeks I re-wrote the narrative. On completion I felt rather pleased with myself. Together Joyce and I had written what I considered to be an illuminating life story. We had shared responsibilities. Joyce had also strengthened my position as researcher and improved my writing. In reflecting on phenomenologically grounded research, Heshusius (1987) acknowledges that:

> 'Research is exceedingly demanding... it requires one [the researcher] to be deeply interested in the lives of the persons one

wants to understand ... This approach to research requires *investment of oneself*' (My italics, in Craft 1987 p43).

In addition, narrators themselves have a vested interest in the presentation of their own stories. Left at this stage of the writing process, I believed that I had reason to view the research relationship as relatively collaborative, perhaps even empowering. Joyce and I had developed a similar research relationship to the one Sparkes' (1994, p170) had with an narrator:

> 'What might have been defined as an impediment (our differences) in terms of the development of collaboration has been used as a resource to enrich the collaborative nature of the interaction'

The story stopped here for four of the narrators. With Joyce Kershaw there was a further twist in the research tale.

Joyce writes her own - Life story 2 'Joyce's story'

Rejecting collaboration

I had posted the second draft to Joyce some days before we met up in a local café (see *Appendix 3, 7*). As Joyce came in from the cold, she greeted me with a whack around the head from her scarf. 'I'm fed up with you', she said with a glint in her eye, 'I thought blow it - I'll write me bloody own'. She produced my story from her handbag, and placed it on the table. I turned over the bound sheets and saw that she had hand-written her own story on the back. 'There's twelve pages in all, I wrote it over the weekend'. 'That's great', I acknowledged, 'You writing your own'. I surveyed her

story. It was marvellous. But what did she reckon to mine? Joyce told me that she had only read the first few pages, 'I got fed up with it'. First, she told me that I'd got certain parts of her life story, 'Not quite right'. 'I wasn't upstairs with my Mother like you put down, I was already downstairs with her'. Second, she still did not approve of the narrative style. 'You keep repeating things', she told me, 'if you write it, then you've got to write it like *I do*'.

Negotiating collaboration

I asked Joyce what she thought we should do with the two stories. I told her that she could do whatever she wanted with mine; still use it, use bits of it, or get rid of it altogether. I reminded her that there were things she had told me in the interview that were in my story but absent in her story. She replied:

> 'Well, use mine and add bits from your story but *write it like I would*'.

I told Joyce that I couldn't write like her. I could try but ultimately it would still be my story. She thought for a while and then suggested, 'Okay, I tell you what. Put your story first - 'Danny's story' - then 'Joyce's story' after it'. This seemed like a fair compromise. I then asked her, 'What would you like to tell the reader?' Joyce's answer now appears as a statement presented before her life story in chapter 6. My story is in *Appendix 3, 5*.

Stopping writing

Negotiations continued. Referring to her story she told me, 'I know I keep going back to the old days, it's just I keep adding something else I've remembered'. She told me that she was going to start keeping a diary, 'A record for the future'. Towards the end of her story I noticed that she'd written me a note:

> 'I know there will be a lot more to say as time goes by. I might write again soon'.

I asked Joyce if this meant that she hadn't finished her story. 'For the time being anyway', she replied. I told Joyce of my plans to start writing up my thesis, which would include her story, as soon as possible. She understood and remarked, 'I suppose I could go on writing for ever!' For the time being she was happy for me to use what she had given me. Finally she wanted me to put the spelling right, 'I was tired when I wrote it', and to insert the last paragraph earlier into the text, 'Where I have spoken about Sally').

On typing up her story I kept the structure she had imposed on the text. However in certain places punctuation and grammar were changed (full stops where many commas made for a long sentence, quotation marks were included and paragraphs constructed), while names were changed and titles added (e.g. 'Mr Jones' the centre manager). Joyce has told me since:

> 'You know I have to put things in a way that I like. I suppose that's just me'

Don't we all? Joyce accepted my typed version of her story.

Reflecting on Part 4 - Lessons from Joyce Kershaw

Joyce Kershaw left me negotiating a place in collaborative narrative inquiry. In the end someone else writing her story was not good enough. Comparing our stories, some of the same experiences are mentioned. It appears that my story captured a number of Joyce's experiences but I had not presented them in ways that she wanted. There are a number of lessons to be learnt. I had to discuss with Joyce about including my story in the thesis. Joyce shifted the locus of power from researcher to participant, then back to me again. My role was clarified through our discussions. However, following Sparkes (1994, p169) my assumption of the need for a collaborative relationship underscored my perception of the Joyce as disempowered, disregarding her power to determine the nature of the relationship. Plummer (1983, p106) grandly asserts that life story researchers need 'to turn to the tools of the novelist, poet and the artist'. However, to paraphrase Joyce Kershaw, narrative inquiry may benefit further by supporting narrators to 'write their bloody own stories'.

Conclusion

In this chapter I have outlined the stages of collaborative narrative inquiry. These stories of writing stories highlight how writers play about with narrators' words, cutting, pasting and deleting at will. Disclosures are revamped and storied in such a way so that written texts do not resemble the original spoken words. Later, the five narrators became editors. In Sutcliffe's (1990, p21) study a self-advocate urged peers, 'You must begin to tell your stories - tell people what has happened to you'. Collaborative life story constitutes a method in which people with learning difficulties

become involved in the telling of their own stories – sometimes with others, sometimes alone.