Self-advocacy and families: co-researching with people with learning difficulties

Thesis

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SELF-ADVOCACY
AND FAMILIES:
CO-RESEARCHING WITH
PEOPLE WITH LEARNING DIFFICULTIES

Paula Jane Mitchell

Bachelor of Arts (Honours), History
University of London, 1986

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Health and Social Welfare
This thesis examines how adults with learning difficulties experience self-advocacy in their families. I take a qualitative approach, using in-depth interviewing. My work explores participatory research with people with learning difficulties, involving a small group of people with learning difficulties as co-researchers. I use a dialectical materialist understanding of disability, based on the social model. The thesis adds to the recent theorising of learning difficulty. People with learning difficulties are discussed as an oppressed group. The social identity of adults with learning difficulties is that they need care and control, and are like children. Self-advocacy is shown to claim autonomy and adulthood. This thesis argues that self-advocacy challenges the social identity of learning difficulty, but that the oppression of people with learning difficulties is such that their attempts to self-organise are limited.

The thesis examines the challenge to family roles implicit in this. While the principles of self-advocacy apply to home life, in my research practice did not consciously transfer self-advocacy to home. Service influence and the role of advisers were significant. Nevertheless, for my respondents, self-advocacy did impact at home. Day-to-day control at home seemed to be allowed, with real control still resting with parents. The thesis uses models from family literature to illuminate control and autonomy at home. The traditional concept of the 'handicapped family' is undermined by my research. Stereotypes of controlling parents holding back their adult children were not found, but the values of independence and separateness are not desirable to all families or adults with learning difficulties. My work links adult status to the identity of learning difficulty itself, exploring how people define themselves.
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Chapter 1
INTRODUCTION

In this thesis I examine how adults with learning difficulties experience self-advocacy in their parental family home. I take a qualitative approach, based on in-depth interviewing of ten people with learning difficulties, supplementing this with interviews with their parents and self-advocacy advisers, and visits to self-advocacy groups. My work explores participatory research, involving a small group of people with learning difficulties as my co-researchers in all aspects of the research process.

This chapter introduces the research, defines terms, and looks at relevant areas of research interest. I then discuss the methodology and analytical approach, before introducing the structure of the thesis and commenting on terminology.

1. Introducing self-advocacy and families

The topic is likely to be of interest to two key areas within the learning difficulty field: self-advocacy and families. Self-advocacy by adults with learning difficulties is well-established in Britain, with as many as 5000 involved in groups (Mitchell, 1997). Much of the emphasis in self-advocacy writing and research has been on service change, while the issue of how self-
advocacy impacts at home has been rarely addressed. My investigation into self-advocacy and families therefore adds an extra dimension to knowledge of self-advocacy.

General family theory has largely neglected families with disabled members. There is a body of research into families with members with learning difficulties (mainly as children), but there has been only a little attention paid to the perspective of the people with learning difficulties themselves. My examination of self-advocacy and families therefore adds to knowledge about families in three ways: by drawing together general family theory with what is known about families with people with learning difficulties; by illuminating further the experience of families with adult children; and by highlighting the perspective of people with learning difficulties.

My thesis is also of methodological interest. The qualitative methods used are built on relationship-based techniques and in-depth interviewing. My participatory approach applies developments from within disability research to research with people with learning difficulties. My work is at the 'cutting edge' of the current debate about new approaches to learning difficulty research.

Reflexivity is a central feature of this research, explored in the methodology and methods chapters. Atkinson and Shakespeare (1993) discuss reflexivity in relation to three areas: the self, research 'subjects' and practice. It is therefore appropriate to explain my interest in this subject. For thirteen years, before embarking on research, I worked with people with learning difficulties, in both a voluntary and paid capacity, in residential, day and leisure services. My four-year involvement in self-advocacy was as a development officer in social services and then as a self-advocacy worker on an independent self-advocacy project. In my own
experience, it was evident that though self-advocacy claimed to be about all of life, and many members of self-advocacy groups lived with their parents, there was little link between self-advocacy and families. While a firm supporter of the principle of self-advocacy, questions were raised for me about its impact on families and home life.

My research question, as to the experience of self-advocacy and families, thus arose from my practice experience in self-advocacy. The principle of self-advocacy (outlined below) suggests that people with learning difficulties involved in self-advocacy might be expected to speak up for themselves at home, both in terms of day-to-day choices and bigger decisions; and that this would inevitably impact on roles, relationships and perceptions. Issues raised in self-advocacy such as jobs, relationships, independence and adulthood would clearly have particular relevance for families. Self-advocacy might suggest that personal changes and achievements outside of the home would be recognised by the family. It might also suggest a certain amount of knowledge of and opinion about self-advocacy in the family. My practice experience, however, suggested that there was little link with or impact at home.

2. Defining self-advocacy

A simple definition of self-advocacy is 'speaking up for yourself' - but defining self-advocacy is not simple. People with learning difficulties themselves have had much to say in defining their activities. Simons (1992a, 1993a) and Sutcliffe and Simons (1993) found a range of interpretations. The most common points are: having a voice of your own; forming opinions and making choices; being listened to and taken seriously; learning new skills; valuing yourself; taking action; changing services; changing attitudes; rights, responsibilities and risks;
and being part of the real world. Crawley (1988) explains that self advocacy can encompass small daily decisions and life-changing choices, from having a say in the day-to-day delivery of a service to taking up disability issues. Self-advocacy can take place either individually or with groups, but rather than being mutually exclusive, experience in a group can lead to greater confidence as an individual, and vice versa.

Self-advocacy has a thirty year history, discussed in chapter 2. Self-advocacy takes place in an organised fashion in groups, both situated in services and independently. Crawley (1990) suggests a typology of groups: service-based (e.g. day centre user groups); independent (e.g. People First); divisional (i.e. part of a larger organisation, such as Mencap's Participation Forum); and coalition (i.e. linked with other campaign groups, such as disability coalitions). In my experience this typology is a little rigid, since there are really many more kinds of groups, though most tend to be broadly either service-based or independent.

Self-advocacy is a 'movement'. Groups have linked themselves within and across states in North America since the 1970s and internationally for fifteen years. People First London, a self-funded body, has since the beginning seen one of its functions as encouraging the formation of other groups and working to link them together (King's Fund, 1985). There are national People First organisations in Ireland, Wales and Scotland, and there have been various attempts to establish an England and now United Kingdom People First. Ideas and material are disseminated through newsletters, conferences, workshops, etc., both directly to people with learning difficulties and indirectly through supporters and staff.
Most service groups take place in day centres, although there is a growing number attached to other aspects of services also, such as housing schemes. Independent groups tend to go under the name of People First, to link themselves to the national and international movement. They can be facilitated by independent advocacy schemes, voluntary sector bodies, the London People First organisation, and service workers in their spare time. Some service groups also take on the name People First to associate themselves with the movement, but strictly speaking are not independent. Of the ten people with learning difficulties I interviewed, three were members of independent People First groups, three of service groups, three of both, and one was a member of a group attached to an independent leisure scheme. I visited all the groups bar one.

Most self-advocacy groups are supported by non-disabled people in the role of adviser. They have a specific role which includes facilitating group meetings, offering guidance and advice, helping members learn skills and giving practical assistance. The national learning difficulty agency Values Into Action (VIA) has identified the crucial role of the adviser (Dowson and Whittaker, 1993), though, as Walmsley points out (1997), the role is under-researched. Goodley pursues an interesting examination of the adviser's role (in press). In my research I interviewed advisers in order to gain a fuller picture of the respondents' self-advocacy involvement. Some groups have other types of support. Two of the groups had advisers who themselves had learning difficulties, and they had non-disabled supporters. It was the latter whom I interviewed. One of the groups was established to take part in a national project facilitated by the King's Fund. The members with learning difficulties were supported by a service worker, whose job it was to facilitate their involvement. I interviewed this service worker. One of the user groups lost its adviser (whom I interviewed) part way through the
research, and I interviewed the manager of the day centre, who kept a watching brief on the group.

3. Relevant research areas

Several areas of research have influenced this work, all of which are discussed in depth in the two literature chapters:

- disability theory
- care and control
- self-advocacy
- user involvement
- normalisation
- family theory
- community care
- adulthood and identity

I will now briefly introduce each of these.

Disability theory

I use a materialist understanding of disability, based on the social model (e.g. Oliver, 1992). I take a dialectical approach, in other words, that nothing is fixed and that various factors interact with each other to shape and change experience. Recent debates in the disability movement, around the reality of impairments which cannot be alleviated totally by removal of
social barriers (e.g. French, 1993a), demonstrate the importance of this dialectical approach, especially in regard to learning difficulty. Learning difficulty itself is only recently being theorised (e.g. Williams, 1989) and my work adds to this. People with learning difficulties are discussed in this thesis as an oppressed group, whose oppression is complicated by the reality of learning difficulty.

Care and control

I have turned to debates about care and control, for example, Cohen and Scull (1983) and Trent (1994), to throw light on the social perception of adults with learning difficulties as in need of care and control, and being like children. The argument of this thesis is that self-advocacy challenges this social identity of learning difficulty, but that the oppression of people with learning difficulties is such that control is exerted even over their attempts to self-organise. The thesis also examines the challenge to family roles implicit in this.

Self-advocacy

There has been some empirical research interest in self-advocacy (e.g. Crawley, 1988), but there is a wealth of material produced by those directly involved, both people with learning difficulties and practitioners. The emphasis of much of this work is service change. However, the claims made for self-advocacy demonstrate the significance of skills and achievements that relate to the whole of life, and which are also strongly associated with adult status. These claims point to the relevance of self-advocacy to families.
Over half the adults with learning difficulties in Britain live with their parental families (Simons, 1992a). Despite this, the question of how self-advocacy impacts at home has rarely been investigated. As has been warned by some writers (for example, Dowson, 1990) the service influence on self-advocacy has been heavy, sometimes benevolent, sometimes purposefully controlling. This can be seen to have pulled the interest of self-advocacy away from other aspects of life. The role of advisers is also significant. This thesis discusses the role of services and advisers in determining the agenda of self-advocacy.

User involvement

User involvement in services is an area where there are competing discourses. Service change is extremely important in self-advocacy (Whittaker, 1993), and the 1980s saw a flourishing of user groups and a rejection of the perceived paternalism of welfare services (Croft and Beresford, 1990). However, Simons found (1992a) that self-advocacy groups felt they did not have much power. The 1980s and 1990s have seen a change in the political context, with the New Right agenda promoting the market, individualism, consumer choice and the right to exit, in place of local authority provision and collective accountability and action (as discussed by Beresford and Croft, 1993; Taylor et al, 1995). This has allowed a blurring of meanings and control, and increased the power of services over self-advocacy.

User involvement has also led to significant advances in people with learning difficulties making demands on services, in particular, carrying out evaluations. This latter development, user-led evaluations, has in turn been a spur to the involvement of people with learning difficulties in research production.
Normalisation

Normalisation, as propagated by Wolfensberger (1972 and 1992), is important in this study because of its highly influential role in setting the agenda for services and research (Chappell, 1992). Wolfensberger has an ambivalent attitude to self-advocacy. In promoting the idea of people with learning difficulties having access to a 'normal' lifestyle, normalisation has been tied to self-advocacy (by, for example, Williams and Shoultz, 1982; Crawley, 1988). However, the emphasis in normalisation on discouraging people with learning difficulties from associating with each other (suggesting instead mixing with non-disabled people) militates against people coming together in groups. Wolfensberger's reformulation of normalisation as 'social role valorisation' (1992) emphasises people with learning difficulties being encouraged to take on socially valued roles rather than express choice. Additionally, normalisation is a theory which focuses on service settings. This in itself has added to the attention on services in self-advocacy.

Family theory

Mainstream work on families is useful for models of families and the transition to adulthood, for example, in Brannen et al (1994), and for understanding the control function of families (Creear, undated). But in the main, family theory seems to set apart families with disabled members. Feminist writing on the family, such as Finch (1984a), has tended to characterise disabled people as a burden. This has been countered by disabled writers, for example, Morris (1991).
There is a tradition of emphasis on stress and other negatives within the literature on families with members with learning difficulties (e.g. Pahl and Quine, 1987). This tends to reinforce the idea of the separateness of such families, and is counteracted by stories of joy and survival (e.g. Bochenski, 1995). My thesis suggests that the more rounded-out studies such as Wertheimer (1981) and Walmsley (1996), focusing on the complexities, are more useful to the study of self-advocacy and families.

Community care

Community care is important to this work both in regard to self-advocacy development and to families. The rhetoric about increased choice in the 1990 National Health Service and Community Care Act has been shown by research not yet to be a reality (e.g. Wistow, 1994; Singh, 1995). Nevertheless, self-advocacy is now 'official' and Simons has pointed out the risks of this in terms of increased service control (1992b).

Community care is also important regarding families. Smith and Brown (1989), for example, have shown that community care idealises the family and increases the burden of care, particularly on women. An effect of community care may be to keep people with learning difficulties in their families longer, with extra pressure on an idealised vision of the family.

Adulthood and identity

Most of the literature on adulthood relates to 'normal' people. Research with disabled young people (e.g. Centre for Educational Research and Innovation (CERI), 1986 and 1988) and
young people with learning difficulties (e.g. May and Hughes, 1988a and b) demonstrates that young people with learning difficulties do not achieve the same 'markers' as others. Issues of independence and autonomy are important in this regard. The disability literature (Oliver, 1990; French, 1993a) has stressed the distinction between independence and autonomy: arguing that it is not independence from assistance that is required, but control over that assistance, i.e. autonomy.

Jenkins (1989) has argued that the social identity of learning difficulties denies adult status. My work explores the adult status of people with learning difficulties and links it to the identity of learning difficulty itself. The effects of labelling are shown by, for example, Eayrs et al (1993). My work discusses the theories of Edgerton (1993) regarding denial, and Goffman (1968) in relation to stigma, to explore how people define themselves. Shakespeare (1996a) argues that disabled people, once conscious of society's disabling effects, can redefine their identity. This thesis argues that some people with learning difficulties reject that label and claim adulthood instead.

4. Methodology and participatory research

The aim of my research was to be part of the new approaches to learning difficulty research. The issues introduced here are developed fully in chapters 4, 5 and 6. The qualitative methods I have used are built on relationship-based techniques, such as those used by Atkinson (1988) and Walmsley (1995), and in-depth interviewing, as developed by Booth and Booth (1994). A body of research with people with learning difficulties has for some time been influenced by feminist understandings of power in the research relationship. Methods such as in depth and
biographical interviews have been adopted to make research a less exploitative and more valuable process.

My research is different from much traditional research with people with learning difficulties due to its participatory nature. Participatory research is the involvement in the research process of people otherwise seen only as subjects. My approach applies developments within disability research (Oliver, 1992; Zarb, 1992) to research with people with learning difficulties. Participatory research, and its relation to emancipatory research, has been the subject of debate and practice in disability research since the late 1980s. However, it is only recently being applied to people with learning difficulties (though the growing experience of service evaluation by people with learning difficulties is linked).

Much current writing on participatory research with people with learning difficulties is either tentatively exploratory (e.g. Williams, 1996) or necessarily propagandistic (e.g. Barton, 1996); there is little in the way of reflexive discussion of real practice (the only examples of which I am aware are Walmsley, 1997, and Stalker, 1998). This thesis therefore makes a contribution to developing research practice with people with learning difficulties.

5. Analysis

My starting point is that involvement in self-advocacy must have an impact at home, no matter how unconsciously, for those members who live with their families. This impact will be conditioned by a number of factors, including the nature of the self-advocacy involvement itself, the level of conscious effort to transfer self-advocacy to home, the experiences and
attitudes of family members, and factors such as age, gender, ethnicity and class. In this thesis I address three areas: the self-advocacy context, the family context, and the question of identity. The first two areas I planned to address in advance; the third aspect arose directly from the study. There is, therefore, a grounded element to this work (Glaser and Strauss, 1967), in other words, issues and theory have arisen from the data. It is of course not possible to leave to one side entirely the assumptions with which a researcher enters a field, but I attempted to allow my investigation to be shaped as much by issues that arose from it as by my assumptions at the start.

I examine the perspective of the people with learning difficulties, but, in order to aid understanding, I also sought the viewpoints of parents and self-advocacy advisers. However, the people with learning difficulties are central. For example, the testimonies of the two people with learning difficulties whose parents I could not meet stand in their own right.

6. Structure of the thesis

The structure of the thesis is balanced between the dual foci of participatory research and self-advocacy and families. The first literature chapter, chapter 2, discusses disability theory, and issues of care and control. I then address self-advocacy, its claims, history and influences. The chapter includes an examination of the policy contexts of user involvement, normalisation and community care. I argue that the oppression of people with learning difficulties is such that self-advocacy has, to a degree, been controlled by the interests of services and the influence of the individual model of disability. One result is that while adulthood and families are integral to self-advocacy, the emphasis in practice has been on services.
Chapter 3, the second literature chapter, investigates the relationship between families, adulthood and self-advocacy. General family theory is shown to pay little attention to families with learning disabled members, while there is a sizeable separate body of literature specifically on such families. I return to community care and debates around care and control to help reach an understanding of the function of families. I argue that there is an expectation on families that they will both care for and control their adult children with learning difficulties. The experiences of families are such that the reception for self-advocacy will be very ambiguous. I argue that self-advocacy, in its claims to autonomy and adulthood, challenges much of the basis of families with adults with learning difficulties.

Chapter 4 is the methodology chapter, justifying the dual approach of qualitative and participatory research. It looks at the developing traditions of learning difficulties research, justifying my qualitative approach. I explore the discourse and practice in disability research of participatory and emancipatory approaches, and discuss the still very new application of these ideas to research with people with learning difficulties.

In chapter 5, I take a reflexive approach to my experience of co-researching. I discuss finding co-researchers, dealing with issues of criteria for inclusion, access, consent and negotiation. I then address the over-arching issue of the relationship between the co-researchers, myself and the research. Particular aspects of the process are focused on: involvement in theory, planning and design, fieldwork, analysis, and writing and presentation. The chapter shows how this project has extended participation to two areas - theory and analysis - previously considered
particularly challenging, and has developed the experience of other researchers in terms of writing and presentation of results. Issues for further exploration are raised.

Methods employed in the qualitative investigation are explained in chapter 6. A reflexive approach is central, in terms of my awareness of the respondents, reflecting on the research plan and process, and being aware of the relationship between the respondents and myself as both researcher and person. The respondents are introduced in this chapter. The importance of careful planning of the fieldwork process, and of flexibility in practice, are both demonstrated here. Issues arising from the research relationship are addressed, such as access to and consent of respondents, getting to know people, exploitation, giving something back, joint interviewing and withdrawing. The chapter also discusses analysis, and issues of reliability, validity, replicability and generalisability.

Chapters 7, 8 and 9 explore the findings of the research in three areas respectively: the self-advocacy context, family context and identity. Two themes run through these three chapters: crossing boundaries, and the difference between the surface picture and the reality underneath.

In chapter 7, I use the distinction between principle and practice to demonstrate that, while the principles of self-advocacy apply to families, practice does not consciously transfer self-advocacy to home. The role of advisers and the influence of services in this are explored. The chapter also discusses the control exerted by people with learning difficulties over the transfer of self-advocacy to home, and explores the responses of families to self-advocacy.
Chapter 8 employs models from family theory to help understand the experiences of families in which an adult child stays at home. The chapter discusses the experiences and conditions of families and the experience of 'speaking up' and autonomy at home. I show how my respondents with learning difficulties felt that they had day-to-day control at home, but that this can be seen as allowed control and that bigger issues caused more difficulties. The advisers put forward the idea that people with learning difficulties involved in self advocacy lead double lives. This chapter shows that I found double lives, but also that people's lives are complex, with interactions of different factors, and that lives do not stay the same.

In chapter 9 I examine the related concepts of independence and identity. I show that the stereotype of families holding on while adult children struggle to move away is not found. The distinction between independence and autonomy is crucial in this discussion. My respondents largely had not attained the traditional markers of adulthood. Nevertheless, they claimed an adult identity, and some rejected the label learning difficulties as incompatible.

These three areas are drawn together in the conclusion in chapter 10. The contribution of this research, both in content and methodology, is underlined. Recommendations are made for further work.

7. Terminology

'Labels are different in different countries. We say mental handicap and Angela from Liverpool said it should be learning difficulties. In America they say retarded. Lots of people were very upset and crying about the names they get called. I think labels mean people make fun of you. They should stop doing it. They should scratch it out.' (People First Manchester, 1993a)
Whatever the particular label, the words used to describe people can arouse great emotions, as the experience above at the Third International People First Conference shows. In the self-advocacy movement, labelling has been a central issue. People First Wales, for example, cite, 'make sure we are not called names we don't like, such as "mental handicap"' (Kurowski, 1993, p.2) as one of the reasons for their existence.

It is therefore right that in this research consideration is given to the words which are used. It must be remembered, though, that although words and labels have been very important within the self-advocacy movement, they are not at the heart of the matter. Beresford and Croft warn against lip-service, 'learning to say the right thing, while continuing to do the wrong one' (1988, p.21). Dowson (1990) remarks that while changes in labels are important, they are also an easy change to make: people can still be oppressed, whatever their label. The issue of labelling and identity is addressed in chapter 3.

Learning difficulties

A few years ago this discussion would have been between 'mental handicap' and 'learning difficulties'. The debate has now moved on. The main achievement cited in self-advocacy literature in the early 1990s was the commonly accepted change from 'mental handicap' to 'learning difficulties'. The term was seen as less degrading: 'If you put learning difficulties then they know that people want to learn and be taught how to do things' (respondent in Simons, 1993a). The choice is now between 'learning difficulty' and 'learning disability'. The government terminology is now 'learning disability', and this has been taken fully on board by services. While undoubtedly an improvement on 'mental handicap', it is seen by many in the
self-advocacy movement as inadequate and an example of how those in power have not listened properly. It is ethical that research into self-advocacy uses the labels preferred by the people who have to live with them (as argued by Dowson and Whittaker, 1993).

As well as the ethical question, there is a theoretical argument against 'people with learning disabilities' and in favour of 'people with learning difficulties'. The social model of disability, in which this thesis is located, asserts that it is not the impairment that causes disability, but society. Thus the disability movement prefers the term 'disabled people' rather than 'people with disabilities'. This is more than semantics; it is a statement about the source of disability. 'People with learning difficulties' describes the impairment; 'people with learning disabilities' places the disability within the individual.

However, it should be pointed out that the terminology used by the people so labelled is changing. I have noticed large numbers of the people with whom I have worked adopting the term 'learning disabilities' themselves (and in fact some have corrected me when I have said 'learning difficulties', informing me that 'it's learning disability now'). This may be pragmatism - the battle over labelling is half-won and there may be other issues that are now considered more important. I suspect rather that it is indicative of the level of oppression experienced by people with learning difficulties that the ease of using service jargon supersedes their previous campaigns about labels. It demonstrates the power of services in people's lives, but also suggests that 'learning difficulties' may soon be replaced as the preferred term.

I continue to use the term 'learning difficulties' as the one currently favoured by the self-advocacy movement and, in my view, theoretically correct. However, 'learning disability' is
now in common usage in services and much research, and so I use it occasionally when referring to the work of others.

User

'User' is probably the most common term applied when discussing people in relation to services. It is generally preferred to 'client', which Beresford and Croft (1988) and the User Centred Services Group (1993) argue describes a relationship in which one accepts the dominant role of the professional worker.

However, 'user' brings with it problems. It is sometimes applied to everyone with learning difficulties, as though they all use services, which many do not. Objections are also made that 'user' has connotations with drug use, or that it suggests a passive role, or one in which people give nothing back (The User-Centred Services Group, 1993). Other terms currently in vogue, as part of the emphasis on market values, are 'consumer' and even 'customer'. I believe these words imply a relationship of power and choice which simply does not exist. As has been discussed in a range of literature on community care and contracting (e.g. Hawker and Ritchie, undated), community care is about addressing needs as determined through an assessment. When people with learning difficulties receive a service they are not purchasers aiming to satisfy wants and so cannot be considered consumers.

I use the term 'user' only in specific relation to services.
Self-advocacy

This term itself is one about which there is some contention. It is without doubt a professional term. As a self-advocacy development worker, I often found myself teaching people the words (which many people had great difficulty pronouncing), explaining it as 'speaking up' and wondering why I did not just call it that.

Part of the reason why we do not just call it that, is that in practice self-advocacy is actually far more complex, and just calling it 'speaking up' is belittling. We also are operating in a world in which 'self-advocacy' is now the common international term. Nevertheless, as Dowson has stressed (1990), it is important to acknowledge that it is jargon; a term not in common use (the rest of us just talk, or assert ourselves, or complain) and which suggests that the people who actually control it are the professionals and academics.

Again, as Dowson points out, self-advocacy is not only jargon, it is also a label. Academics and practitioners talk of 'self-advocates'. It seems to me that this suggests that self-advocacy is what people are - everything about them is subordinated to the fact that they are a member of a self-advocacy group. This implies two things - that a 'self-advocate' 'self-advocates' all the time, and that other people who are not 'self-advocates' do not at all. It seems particularly important in this research, where I investigate whether people who are involved in self-advocacy in one part of their lives do the same in another, not to use a label that automatically suggests that they do.
8. Conclusion

This chapter has outlined the arguments, themes and structure of this thesis. The thesis has a dual focus, to use participatory research in order to explore self-advocacy and families. It makes a significant contribution to each of these areas, as well as to the theorising of learning difficulty itself.
Chapter 2

LITERATURE REVIEW:

PEOPLE WITH LEARNING DIFFICULTIES

AND SELF-ADVOCACY

1. Introduction

The purpose of this chapter is to review the literature on self-advocacy and place it in a theoretical framework. The argument presented is that while self-advocacy can be linked to movements of oppressed people, the oppression of people with learning difficulties is such that self-advocacy has to a degree been controlled by the interests of services and the influence of the individual model of disability. One result is that while self-advocacy is, by its own claims, to do with 'all of life', the emphasis in self-advocacy has been on services.

My analysis is placed within a dialectical materialist understanding of disability, based on the social model. The chapter begins with a discussion of the social model and the application of this to people with learning difficulties. This incorporates a discussion of the social identity of people with learning difficulties as in need of care and control, and like children. Section 3 introduces the self-advocacy literature, placing it within the growing 'politics of participation'.

In section 4, I demonstrate that the claims of self-advocacy both implicitly and explicitly apply to families, with achievement of adulthood as a central theme. There has been little
examination of this in the literature. Thus self-advocacy challenges the social identity of learning difficulties. (Adulthood and identity will be developed further in chapter 3.) Section 5 explores the development and context of self-advocacy, involving discussion of normalisation, other forms of advocacy, user-involvement and community care. I demonstrate how the context both supports and inhibits self-advocacy, but has ensured its concentration on services rather than families or other aspects of life.

2. Disability theory and learning difficulties

This section discusses the framework I use in this thesis. I take a dialectical materialist approach to learning difficulty, using the social model of disability as a basis. Abberley commented in 1987 that disability had been under theorised. The last ten years have seen the development of a rich debate, though it remains on the margins of sociology (Oliver, 1996). However, at this stage learning difficulty is on the margins even of the disability debate (Chappell, 1997). This section develops an understanding of people with learning difficulties as an oppressed group and discusses the social identity of people with learning difficulties as in need of care and control.

The model of disability on which are based popular consensus, medicine and 'officialdom' (for example, the Office of Population Census Surveys and disability legislation; Chadwick, 1996), is an individual model. This means that disability is ultimately reducible to the individual person and her or his impairment. An individual's impairment leads to disability, and he or she is dependent on others. In this model, the need for personal assistance carries with it an implication of lack of control. Learning difficulty has historically been explained using the
individual model: 'The subnormality of the individual, rather than the subnormality of the environment, tends to be blamed for any inadequacies' (Ryan and Thomas, 1987, p.27).

The value of a materialist approach is in placing experience in its historical, economic and political context. Disabled writers such as Finkelstein (1980), Abberley (1987) and Oliver (1989, 1990) have developed a social theory of disability. This explains disability as a social construction and as oppression. Disability is historically and culturally specific, a product of the mode of production and its attendant ideology. Thus the modern condition of dependency is a product of industrial society. The social theory shifts the emphasis from individuals and their impairments to disabling environments. It is not the individual's impairment that disables but society. In place of dependency, the social model argues for autonomy - the point is not to do without assistance, but to control it. (The materialist method is still being developed to understand the history of disability, e.g. Barnes, 1996; Abberley, 1996; Gleeson, 1997).

There is wide-ranging debate, often from a feminist perspective, calling for a renewal of the social model to take account of the lived, personal experience of impairment (French, 1993a; Crow, 1996; Keith, 1996). Attention is also paid to psychology (Finkelstein and French, 1993), discrimination (Barnes, 1991), prejudice (Morris, 1991), imagery (Barnes, 1992a) and identity (Shakespeare, 1996a). Moving in a postmodernist direction, Shakespeare (1994) has analysed cultural representation of disability.

There is debate as to whether exploration of difference dilutes the effectiveness of the social model (this debate is outlined by Shakespeare and Watson, 1997). It is not a question, in my view, of having to move away from a materialist standpoint to incorporate the personal
experience and impairment. As Abberley explains (1996), impairment itself is materially and socially constructed. A dialectical materialist approach avoids a crude opposition between the person and society: people are social beings and experience is a product of interaction between personal and social, agency and structure.

However, it is regrettable that people with learning difficulties are largely marginalised in the disability literature. This is despite People First joining the British Coalition of Organisations of Disabled People in 1994, considered by some to be taking the movement 'down a very dynamic path' (Campbell and Oliver, 1996, p.203). Some people with learning difficulties discuss disability theory - for example, Aspis (1997) discusses internalised oppression - but the voice of people with learning difficulties is absent in disability debates (The Powerhouse in Morris, 1996, is a rare exception). There has been some application of the social model to people with learning difficulties, by academics with a specific interest (Williams, 1989; Chappell, 1992 and 1994; Clegg, 1993; Walmsley, 1994).

Even before the development of the social model, writers discussed the social construction of learning difficulties. Through ethnographic studies, Edgerton (1967) and Bogdan and Taylor (1982) concluded that the label mental retardation is social. Bogdan and Taylor question whether there really is a phenomenon of mental retardation: 'Many of the so-called retarded do not possess the imperfections and characteristics that have been attributed to them' (1982, p.3). Edgerton's position, however, is to accept social construction but also to recognise the reality of the impairment.
The history of learning difficulty is under-researched, itself a sign of marginalisation.

Wolfensberger has discussed the different constructions of learning difficulty at different times in history: 'other', non-human, menace to society, object of ridicule, object of pity, burden of charity, eternal child, diseased, and dead or dying (1992). To the needs of the industrial revolution, discussed by Oliver (1990) and Ryan and Thomas (1987), Walmsley (1994) adds the development of literacy as a further process by which people with learning difficulties were marginalised. Williams (1992) highlights that people with learning difficulties were not just characterised as failed workers but also failed parents. Brown (1994) demonstrates that people with learning difficulties were also segregated due to the perceived moral dangers of their sexuality. Eugenics and the 20th century mass incarceration of people with learning difficulties have been analysed as a product of modernity (Radford, 1994) and of the social and economic needs of the capitalist system (Williams and Walmsley, 1990). It is no accident that the 1913 Mental Deficiency Act occurred in the same period as the 1905 Aliens Act - a struggling system, with fears about the quality of the population, was targeting the 'enemy without' and the 'enemy within'. The scapegoating purposes of the Act can be seen in the link between feeble-mindedness and receipt of Poor Relief. Only now is the social history of learning difficulties being recorded from the perspective of the people themselves (e.g. Atkinson, 1993; Atkinson et al, 1997).

Williams (1989) opens a discussion about understanding people with learning difficulties as an oppressed group, though this discussion has yet to fully develop. (Some development of the discussion has taken place regarding disability in general, for example, in relation to nursing practice; Northway, 1997). The common experience of people with learning difficulties is increasingly well-documented: congregation and segregation in large-scale institutions, or
special provision in the community, such as hostels, group homes and day centres (Wolfensberger, 1972; Open University, 1990). The majority of adults with learning difficulties living independently in the community live in poverty (Davis et al, 1993) and isolation (Flynn, 1989). In practice they lack citizenship (Walmsley, 1991a) and their lives often have little sense of purpose (Jahoda and Cattermole, 1995; Brandon and Brandon, 1995). People with learning difficulties have been denied adult status (Jenkins, 1989) and have had all aspects of their lives professionalised (Baistow, 1995). Until the development of self-advocacy, people with learning difficulties had little opportunity to speak for themselves (Williams and Shoultz, 1982).

The oppression of people with learning difficulties is complicated by the existence of cognitive impairment. Application of the social theory to learning difficulty requires a dialectical approach. French's discussion (1993a) of the reality of an impairment which will not disappear through social or environmental manipulation is pertinent to learning difficulty. Discussion of the reality of impairment is new on the disability theory agenda (for example, Morris, 1996) and is necessarily cautious because of the risk of leaving the way open to a return to an individual approach. Whether or not somebody so labelled has an impairment can be a social construct. Women particularly were labelled as impaired and institutionalised due to what was considered moral laxity and inability to support themselves (Williams and Walmsley, 1990).

Nevertheless, the reality of intellectual and learning impairment for the majority so-labelled has to be understood in order to understand the experience. Williams (1989) points out the need to distinguish between the social construction of learning disability as a problem and the
specific needs of people with learning difficulties for social, economic and political support.

An acknowledgement of the reality of impairment raises the question of severity of
impairment. Self-advocacy has so far tended to only encompass people with less severe
impairments, though the boundaries are constantly moving (for example, Sanderson's 1995
discussion of the development of self-advocacy opportunities for people with profound and
multiple impairments). This chapter returns to this in reference to other forms of advocacy (in
section 6). It is a point particularly important in the discussion in chapters 4 and 5 about
participation in research.

The social identity of people with learning difficulties is important in order to understand the
context for self-advocacy. People with learning difficulties are defined as in need of care and
control, for their own and society's protection, and to justify this, infantilised. 'Care and
control' originates in the justification for early approaches to learning difficulty. An outline of
the care and control debate in the period of the development of policies on learning difficulty
can be found in Cohen and Scull (1983) and Trent (1994).

Approaches to people with learning difficulties have had both care and control elements to
them. As Brown points out (1994), 19th century philanthropists, such as L'Arche, worked
from a religious imperative, seeing a need to protect 'innocents' from society. On the other
hand, growing numbers of dispossessed, unemployable people raised the need for a
scapegoat. Policies also had to 'protect the outside world from the social, moral and "racial"
threat which people with learning difficulties were seen to represent' (Williams, 1992, p.152).

Women with learning difficulties in particular were stereotyped as 'immoral, carriers of
venereal disease, bearers of defective children, promiscuous, over-fertile and a cause of
potential social, economic and moral decline...' (ibid., p.153). These influences have been the ideological basis for service provision, rooted in an individual model of disability which sees these two needs of care and control as stemming from the disabled person. Community care has inherited these functions. Though idealist, Foucault's ideas on social control (1980) are helpful for understanding the multi-layered, all-pervasive character of control.

The power of services to maintain dependency and control is evident at all levels. The dependency of disabled people created by industrial society (Oliver, 1989) is particularly perpetuated by services, where the ideology of care has predominantly meant taking responsibility (Morris, 1994). Barnes argues that policies create dependency 'by not providing [disabled people] with the confidence, practical and intellectual skills' (1990, p.203). Glendinning has demonstrated the negative effects that policies can have, which in the 1980s 'intensified scrutiny and control' by professionals and others (1991, p.38). Baistow describes the 'colonisation of ordinary life' (1995, p.38), as all aspects of life are problematised, and professionals develop career structures around the lives of people with learning difficulties.

Lipsky's theory of 'street-level bureaucracy' (Hudson, 1989) analyses the power of staff such as social workers. In this theory, due to their exercise of discretion, front-line workers have significant control over users. Aspis, a campaigner with learning difficulties, explains how internalised oppression of people with learning difficulties gives staff power:

'...when growing up, people with learning difficulties learn that professionals are helpful and supportive by the one to one attention they receive... The bare fact that a service provider nods or passively listens to a person with learning difficulties makes him or her feel valued.' (1997, p.653)
Alongside the control must be remembered the 'care' - that many workers genuinely want to
better the lot of people with learning difficulties. Nevertheless, the structures and ideologies in
which they operate are based on an individual model which militates against it.

Care and control are intimately linked to infantilisation. Jenkins (1989) demonstrates, through
medical, psychological and behavioural models, law and popular conception, that the view of
people with learning difficulties as eternal children is deeply ingrained in society. The power
relations in the lives of people with learning difficulties involve families as well as services;
families will be discussed in chapter 3.

The reality of impairment and the social identity of people with learning difficulties have
implications for their oppression, particularly in terms of their ability to fight back. The theory
of learned helplessness is useful here (Seligman, 1975), suggesting that if people are
frequently in situations over which they have no control, they can learn to believe that they
can do nothing to change things around them. Aspis expresses the reality of this socialisation,
curbing the ability to fight for a better life:

'Through the labelling process people with learning difficulties have had their
expectations of life limited by other people. They are told to accept what is
"realistic" rather than having the challenge to go for something that is not
available.' (1997, p.653)

Collectivity is also difficult because of the isolation of people with learning difficulties from
each other and divisions made by services between different impairments (Chappell, 1994). I
discuss the normalisation principle below, but one of its effects is disassociation of people
with learning difficulties from each other, due to the conception of mixing with other disabled
people as a problem.
The balance to all this is that people do not just 'take it lying down'. There are many anecdotes of people in institutions sabotaging and resisting (e.g. Atkinson, 1993). Self-advocacy itself is an example of thousands of people with learning difficulties organising. 'Empowerment' is the buzz-word of enlightened professionals encouraging a counter-balance to the control of others. It has a myriad of meanings (Servian, 1996, found ten!) and is often used interchangeably with user involvement and self-advocacy.

Baistow (1995) suggests empowerment commonly means either an individual aim, to be able to control your own life and take part in civil society, or a collective tool to combat oppression. This broad interpretation of empowerment is taken by, for example, Ramcharan et al in a collection addressing all aspects of life (1997). Nevertheless, empowerment is very often given the narrower meaning of shifting power towards users of services (e.g. Winn, 1990). Control is so pervasive that even empowerment is fast becoming a tool of professionals and the justification for service roles. As Baistow says, empowerment becomes something a powerless person needs doing to them - 'deciding who should be empowered is a sign of power' (1995, p.41). Dowson (1997) contrasts empowerment with taking power, arguing that there will be little change without the latter. (This discussion is developed in section 7.)

Many disabled writers advocate collective action to achieve social change (e.g. Oliver, 1990; Corbett, 1994). Self-advocacy is often seen by academics as having this purpose. Williams (1989) and Walmsley (1994) both suggest self-advocacy as a way of achieving change. However, employment of the social model in understanding self-advocacy necessitates a deeper analysis. This chapter goes on to discuss the development of self advocacy, its claims,
history and influences. I show that the oppression of people with learning difficulties is such that power over self-advocacy can lie in the hands of services, and often operates according to the individual model of disability (Goodley, 1997).

This section has discussed the limited application of the social model to learning difficulty. Use of the model to understand self-advocacy necessitates an analysis of the oppression of people with learning difficulties and the care and control identity. People with learning difficulties do organise for a better life, but this discussion suggests that the pervasive control in their lives impacts also on their attempts to organise. The chapter now goes on to examine the self-advocacy literature.

3. The self-advocacy literature

This section discusses the nature of the literature on self-advocacy. I begin by placing this literature in the context of the growing 'politics of participation'. I then discuss the dual nature of the literature and show that there is a focus on service change.

The last few decades have seen a development of the 'politics of participation', recognised by popular media (for example, Livas, 1995; Ghazi, 1995) and academics. We are in an age which postmodernists characterise as the 'end of the expert' (Williams, 1994), including the rejection of claims to absolute knowledge. Beresford and Croft (1993), champions of citizen involvement, explain that public participation has been on the agenda for 30 years. Another feature of the same period has been the expansion of oral history and community publishing (Bornat, 1989). I will discuss more fully in chapter 4 how feminist ideas and the discourse
within user involvement and disability research have challenged 'ways of knowing' and who can be a 'knower' (e.g. Harding, 1987). It is within this context that the literature on self-advocacy must be viewed.

There is some empirical research in Britain on self-advocacy. Seventeen years ago Crawley first investigated trainee committees in Adult Training Centres (1983), and her survey was repeated in 1986-7 (1988). Wertheimer (1989) conducted a study of self-advocacy and families, interviewing parents of disabled people. Simons (1992a) has studied self-advocacy in Bristol, accompanied by a national overview of self-advocacy, drawing on the experience of the National Institute of Adult Continuing Education (NIACE) and the Bristol Advocacy Project (Sutcliffe and Simons, 1993). Sanderson (1995) has examined self-advocacy opportunities for people with profound and multiple impairments, and Stalker (1997) has carried out a case study of a self-advocacy group. In the pipeline is a Ph.D. appraising self-advocacy in the lives of people with learning difficulties (Goodley, 1997).

There is a lack of theorising about self-advocacy. It is frequently put forward as a possible solution or strategy for change, as was seen in section 2, but the discussion rarely goes beyond that to analyse self-advocacy itself. Exceptions are Walmsley and Downer (1997) and Goodley (1997), both discussed further later. Walmsley and Downer examine the diversity of identity of people with learning difficulties and the need for this to be incorporated in the self-advocacy movement. Goodley has applied the social model to self-advocacy, arguing that for it to be effective it needs to be practised from this perspective rather than from the individual model.
There is academic interest in related areas, for example, choice-making (Spackman et al, 1995; Stalker, 1998). The analysis of experiences of women with learning difficulties (e.g. Williams, 1992) has led to academic support for a women's conference (Walmsley, 1993a) and the writing of a book by, with and about women with learning difficulties (see Walmsley, 1997). Academics turn to self-advocacy groups for assistance, for example, Davidson-Paine and Corbett (1995) in a study of gay men with learning difficulties. In the USA, academic interest has focused around, for example, self-advocacy training (Wolfe and Ofiesh, 1996), choice-making (Stancliffe, 1995), and peer-support (Rhoades et al, 1996).

Alongside academia, there is a wealth of material produced by those directly involved, describing and explaining self-advocacy, raising issues, charting history and achievements, and reporting on self-advocacy events. This material falls into two types: reports, books and articles by practitioners; and material produced by people with learning difficulties themselves, either by groups or individuals. The history of people with learning difficulties is usually presented from the perspective of others. This is not the case with self-advocacy, though much of their material is not professionally published or distributed.

Thus there are two debates taking place: one in an academic context and another among people with learning difficulties and their allies. The difficulty with access to publishing is indicative of the power imbalance in these debates. Nevertheless, it is important that the allies include academics. For example, two conferences took place at the Open University in 1997 on the social history of learning difficulty, with people with learning difficulties alongside academics and practitioners as both participants and presenters. As will be discussed in
chapter 4, there is a growing number of academics involving people with learning difficulties in participatory research (to which this thesis makes a significant contribution).

Ramcharan and Grant (1994) point out that academic literature reviews tend to overlook the perspective of disadvantaged people. Given the participatory nature of my research, it is appropriate that this chapter reviews the 'non-academic' material.

Self-advocacy literature has tended to focus on influencing services. This encompasses many aspects:

- individual planning (Sweeney, 1991)
- shared action planning (Brechin and Swain, 1988)
- personal futures planning (Greasley, 1995)
- service brokerage (Nelson, 1991)
- quality action groups (Millner, 1992)
- assessment and choice (People First, undated a and b)
- consultation (People First, 1993)
- involvement in planning (Harper, 1988)
- staff training (Harding, 1995)
- selection of staff (Townsley and Macadam, 1996)
- service evaluation (People First London, 1994a)
- fighting cuts (Calderdale Advocacy, 1993)

User involvement has been the subject of research and a great deal of discussion (e.g. Croft and Beresford, 1990; The User Centred Services Group, 1993). This focus on services is considered to have achieved a change in service culture (Whittaker, 1996).
An estimated 40-60% of adults with learning difficulties in Britain live with their families (Simons, 1992a). Despite this, the question of how self-advocacy impacts at home with families has been little investigated. Simons remarks that most learning difficulty research has focused on those people in residential services, so 'we know very little about the views and experiences of those who have remained at home' (1992a, p.65). A person's involvement in self-advocacy would inevitably have some sort of impact at home - no-one operates within a vacuum. However, the few studies in this area (e.g. Wertheimer, 1989; Simons, 1992a) indicate that there has been little direct link made by those involved (as members or supporters) between self-advocacy groups and home life, and that any unconscious or indirect impact has been very mixed. These studies are reviewed in chapter 3.

This section has introduced the self-advocacy literature, showing that while there is some academic interest there is a wealth of material by people with learning difficulties. A major interest in self-advocacy has been on services. Nevertheless, the discussion of the claims of self-advocacy which follows in the next section shows that self-advocacy applies to families.

4. The claims of self-advocacy

This section demonstrates the centrality of autonomy, adulthood and the 'whole of life' in the meanings and claims made for self-advocacy. Self-advocacy thereby represents a rejection of the social meanings attached to learning difficulty. This section indicates that self-advocacy applies to families.
People with learning difficulties have defined their own self-advocacy activities. While meanings are not homogenous, there are consistent themes:

- speaking up for yourself
- making choices and decisions
- being listened to and taken seriously
- learning new skills and personal development
- taking control of your life
- coming together to share ideas and gain strength
- helping and representing others
- getting information
- being treated as an adult and like anyone else
- rights, risks and responsibilities
- influencing and changing services at all levels
- campaigning against labels and attitudes
- taking up issues, such as work, benefits and sexuality
- social contact and support
- joining with other oppressed groups aiming for social change
- independence and being part of the real world

(Black People First, 1994; Brown, 1992; Calderdale Advocacy, 1993; Huddersfield People First, undated; Inclusion International, 1996; Kurowski, 1993; People First, 1993 and 1994; People First London, 1994b; People First Manchester, 1993a and 1993b; Simons, 1992a and 1993a; Sutcliffe and Simons, 1993; Talbot, 1993; Wertheimer, 1990; Young People First, undated and 1994).
This is an extensive list, but clearly indicated is that self-advocacy is about all of life. Inclusion
International's committee of people with learning difficulties states this unequivocally:

'Self-advocacy is our gateway through to the real world. We want to be part of
our own community, to share both the joys and sorrows life holds for all people.
We want to be the same as everyone else'.

(1996, p.19)

Non-disabled self-advocacy campaigners have also defined self-advocacy. The key points
emphasised are the twin aspects of speaking up and action for change (e.g. Cooper and
Hersov, 1986). Also stressed is that self-advocacy should not be seen as a special activity
confined to special times but is intended to impact on all aspects of life (e.g. Whittaker, in
Wertheimer, 1988a; Dawson and Palmer, 1993).

Self-advocacy is about both individuals and groups. Crawley (1990) offers a typology of
groups, as seen in chapter 1. Brandon et al say there is 'considerable confusion between self
and collective advocacy processes' (1995, p.119), suggesting that self-advocacy implies
individuality. It is certainly the case that many of the meanings of self-advocacy are individual.
Nevertheless, it is the collective nature of self-advocacy that is important - personal gains
follow, but it is from groups that people gain the strength, skills and confidence that enable
them to make changes in their lives. Being able to meet together gives the opportunity for
political action (Chappell, 1994). The importance of this point will become clear in the
discussion about the development of self-advocacy in section 5.

Personal development is the most commonly mentioned achievement. People First Wales, for
example, exists in part to 'help us all gain confidence so we can express ourselves' (Kurowski,
1993, p.2). At their 1993 conference, most of the Welsh groups counted increased self-
confidence among their achievements. They reported that this made them feel more
independent, more likely to want to take responsibility for themselves, more able to try to take control. Nancy Ward, involved in the self-advocacy movement for a long time, explains:

'Before I became involved in self-advocacy, I did not see myself as a person and I had no self-confidence. Now I have learned to speak in public. Self-advocacy means seeing yourself as a person and gaining confidence.'

(Nancy Ward, in Wertheimer, 1990, p.4)

Making day-to-day decisions, dealing with practical problems, and having more control in everyday life are common aims and achievements (Simons, 1992a; People First Manchester, 1993a; Black People First, 1994). For many, self-advocacy is also about making big changes in their lives. Leaving home, independence, integration, personal relationships, jobs - these are all major issues (Southwark Unity, 1995; People First Manchester, 1993a).

There is also the question of rights. 'Rights are things that mean you should be treated fairly... Having rights means being the boss of your own life' (People First London, undated a, p.15). People First Wales are there to 'make sure we know about our rights, and understand them' (Kurowski, 1993, p.2). People First London have produced material to help people with learning difficulties understand their rights (1994c) and to explain rights under the law (People First London, undated b). They explain, 'We have rights and these rights give us power to change things [in] our lives' (1994c, p.1). As Calderdale Advocacy suggest, others need to be educated in order to understand that people with learning difficulties have rights: 'People knowing about our rights makes us feel more confident' (1993, p.32).

Risks and responsibilities are also important. People First Wales aim to 'make sure we are allowed to take risks, because that is how we learn to take more responsibility for ourselves' (Kurowski, 1993, p.2). One astute comment from the Welsh conference was, 'Other people
worry about us more than we do ourselves' (p.27). As Park says, 'We learn from past experiences and mistakes, but if we are babied how the devil can we have past experiences and mistakes?' (1985, p.42). People First London urge:

'Don't always wait for others to get things done for you because that is not having your own responsibility. Get things going yourself. Use your common sense'.

(1994b, p.5)

Family life is discussed in self-advocacy groups, although not very often. The commonest theme is the denial of everyday choice and autonomy, such as depicted by the Something to Say project (1987) and the Young Women's Group at Elfrida Rathbone Islington (undated). People with learning difficulties who spoke to Cooper and Hersov (1986) felt held back by parents, having to prove themselves before they were allowed to do things, and were frustrated at being treated differently from siblings. Inclusion International's committee of people with learning difficulties pays significant attention to families:

'Our families are the most important people in our lives. They will always be there for us but they sometimes have to accept that we are adults like them and need to make our own decisions and have our own say. They need to learn to let us take risks and not to over protect us. Our families give us our identity or place in life. Without them life can be very difficult.'

(1996, p.19)

Being able to leave home is also important and clearly has implications for families. At two conferences of people with learning difficulties, supporters, staff and parents at the King's Fund (Whittaker, 1991), a discussion was held on helping parents let go of their adult children. It was felt that most parents want to see their offspring become more independent but feel anxious when people start speaking up. Marriage, divorce and children were particularly sticky questions. Lower Edge day centre group recorded, 'We've talked about parents stopping us getting engaged' (Calderdale Advocacy, 1993, p.36).
Adulthood is sometimes explicit: Huddersfield People First cite 'Parents that won't let us grow up' as a problem (undated, p.5), while participants at the 1993 Welsh conference felt that 'some parents can be difficult sometimes - they don't think we are grown up - they do not recognise us as adults in our own right' (Kurowski, 1993, p.18). People First London's list of rights includes, 'You have the right to be treated as an adult who can and who does make decisions about your own life' (1994c). Young People First was a project which concentrated on helping young people with learning difficulties attain adult status (Young People First, undated).

Rights, responsibilities, risks, choices, control, confidence, 'independence' - these are the key aspects of self-advocacy. All these aspects raise the issue of autonomy. Stainton defines autonomy as 'the capacity to formulate and pursue plans and purposes which are self-determined' (1994, p.21). 'Independence' as used in the self-advocacy literature has a broad meaning, from going on buses to leaving home. Control seems to be the key to the meaning of independence. In practical terms, it does not mean surviving alone without help, but having control over that help. This distinction between independence and autonomy is discussed by Oliver (1990) and French (1993b). It is independence from the control of others rather than independence from help that people seek. In the self-advocacy literature, 'independence' can therefore be taken to mean autonomy.

Though people with learning difficulties rarely use the term, autonomy is clearly the aim of many of the claims of self-advocacy. People with learning difficulties are more likely to use the terms 'independence' and being an 'adult'. Walmsley found that for her respondents these two concepts were interchangeable (1991b). For most of us, adulthood and autonomy are
seen as synonymous. As Barron asserts, 'we generally associate the onset of adulthood with increased autonomy in everyday life' (1997, p.225). People with learning difficulties explicitly state that having their adulthood recognised is an aim of self-advocacy, especially in relation to families. I therefore contend that adulthood has a central place in self-advocacy, both in the explicit statements and implicitly in the claims of self-advocacy for autonomy.

Claims to adulthood inevitably have important implications for families. In an extensive report on the transition to adulthood, Morrow and Richards (1996) discuss the involvement of families in supporting the transition. Youniss and Smollar (1985) contend that the child's development to adulthood occurs through relationships within the family (as well as with peers and others). Family theory and the transition to adulthood will be discussed in full in the next chapter. These claims to autonomy and adulthood are particularly important when the social identity of learning difficulty is considered. Section 2 showed that the social identity is tied up with notions of care, control and infantilisation. Self advocacy therefore represents a rejection of the meanings attached to learning difficulty.

The conclusion from this discussion of the claims of self-advocacy is therefore that self-advocacy is to do with the whole of life, with adulthood occupying an important position. Self-advocacy thereby challenges the social identity of learning difficulty discussed so far. These elements of self-advocacy further imply that self-advocacy applies to families. The next section discusses the development of self-advocacy, in order to examine how the meanings of self-advocacy and issues of control have played out in its development.
6. The development of self-advocacy

This section traces the history of self-advocacy in Britain, connecting its development to movements internationally, to other forms of advocacy, and to the policy developments of community care, normalisation and user-involvement. I show that people with learning difficulties have received the support of professionals from the beginning. The professional help has been a double-edged sword: both enabling self-advocacy to grow but also enabling influence to fall into the hands of services. This influence can be benevolent, though still restrictive if based on the individual model. Services have been able to pull self-advocacy in the direction of user involvement. Inevitably, given the place services have in the lives of many people, changing them will be of great concern. Nevertheless, this focus has taken attention from other aspects of people's lives (those aspects service workers know less about) and enabled service systems to exert control over the movement. I examine the advisers' role.

Self-advocacy has a 30-year history. Its origins can be traced to the 1950s and 1960s, a period of increased confidence, when civil rights, national liberation and revolutionary struggles swept the globe. These movements touched most oppressed sections of society, from disabled war veterans to revolutionary black youth, struggling for the economic and social reforms they had been promised. The development of disabled people's organisations, such as the Union of the Physically Impaired Against Segregation, was part of this. Exposés of conditions and abuse in institutions (Morris, 1969), new research into the potential of people with learning difficulties and the development of new therapies (O'Connor and Tizard, 1956; Clarke and Clarke, 1958), and the economic costs of large-scale institutions (Scull, 1977), all added to a new impetus to change conditions for people with learning difficulties.
It is within this context that the arrival of self-advocacy can be placed (Whittaker, 1996). The first self-advocacy groups met in Sweden in the 1960s, around a network of leisure clubs. In 1968 the first recorded national conference of 20 people with learning difficulties took place, followed in 1970 with a conference attended by 50 representatives from Sweden and Denmark (Whittaker, 1996). Williams and Shoultz (1982) explain how in the USA small groups of people with learning difficulties moving out of institutions in Nebraska set up support groups in the community.

The year 1971 was an important one in Britain. Following the ethical and economic arguments against institutions, the government published a White Paper, 'Better Services for the Mentally Handicapped' (Department of Health and Social Security, 1971). Though no green light for self-advocacy, its general principles embodied some notion of people with learning difficulties having rights. The same year, 1971, also saw the start of two highly influential organisations, the King's Fund Mental Handicap Project, and the Campaign for Mentally Handicapped People (CMH - now Values Into Action), both committed to empowering people with learning difficulties. These organisations were champions of normalisation, and were instrumental in bringing the theories developed in Sweden and the USA (Nirje, 1972; Wolfensberger, 1972) to Britain. It was these professionals and campaigners who initiated the high-profile self-advocacy developments in Britain.

Normalisation began in Sweden, as a pragmatic policy to give people with learning difficulties normal living conditions and the same rights as other citizens. Wolfensberger, in the US, took these ideas and theorised about a process of social devaluation, which he argued needed to be addressed by:
'...the enablement, establishment and/or defense of valued social roles for people-particularly for those at value risk - by using, as much as possible, culturally valued means'. (Wolfensberger, 1992, p.32)

The ideas of Wolfensberger have been highly influential in the US and Britain. A purity of teaching Wolfensberger's texts has developed which has attempted to stifle debate (see Brown and Smith, 1992), but important criticisms have been made. The theory is criticised for promoting conformity to the roles and culture of an oppressive society (Elks, 1995). Chappell (1992) argues that normalisation fails to give a materialist theory of disability, and is based on improving services rather than addressing the material conditions and power relations which shape people's lives. Although a social theory in that it deals with societal values, the theory assumes disability and social values as given and that the person with learning difficulties has to change (Gleeson, 1997).

Wolfensberger's position on self-advocacy is contradictory. Whereas Nirje suggests self-determination, Wolfensberger subordinates personal preferences to prescribed standards of behaviour - the 'conservatism corollary', whereby within a certain range of options an individual should be encouraged to choose the most conservative (Perrin and Nirje, 1989). Wolfensberger originally appeared to see a value in self-directed groups:

'There is no doubt that segregation is a danger, but this danger must be balanced against the important functions these [self-directed] groups perform'. (1972, p.186)

However, his theory encourages mixing with valued others rather than people with learning difficulties, which cuts across the ability of people to organise. The teaching of normalisation focuses only on services and encourages them to develop according to the normalisation principle rather than the wants of people with learning difficulties (e.g. Wolfensberger and Thomas, 1994).
Nevertheless, normalisation was one of the spur(s) to the policy which supported an 'ordinary life' for people with learning difficulties, and helped set the conditions in which self-advocacy took root. Crawley (1988) is explicit in her belief that part of the reason for the development of self-advocacy groups was a shift in attitudes in line with normalisation.

In 1971 and 1972, CMH organised two Participation conferences, *Our Life and Listen* (Shearer, 1973). These events, following the lead of the Swedish initiatives, made clear how much had to be done to challenge attitudes and struggle away from the sometimes horrific experiences described. The discussion was about families as much as services, but professionals, following their own interests and influenced by normalisation, came away with the conclusion that self-advocacy should be established in services.

The influence of these initiatives spread to North America, where staff organised a conference in 1973 in British Columbia, followed in 1974 by a conference run by people with learning difficulties themselves in Oregon, attended by 560 people (Wertheimer, 1990). The organising group called itself People First. After the conference they organised workshops and launched a newsletter (*Heath et al., 1978*), and the second conference in 1975 was attended by 750 people. The 1970s also saw several meetings in Australia, establishing a movement known as 'Fifth Strand'. The international flavour of self-advocacy is demonstrated in Dybwad and Bersani's 1996 collection of self-advocacy stories from around the world. The first international conference was held in 1984, with participants from the USA, Canada, Australia and the UK. The third international conference in 1993 had participants from 27 different countries (*People First Manchester, 1993a*).
In the USA, People First grew up only loosely associated with services. There was considerable support from parent organisations such as the Associations for Retarded Citizens (Williams and Shoultz, 1982). The parent-led organisation, the International League of Societies for Mentally Handicapped Persons (now Inclusion International), invited 30 people with learning difficulties to run a session at their World Congress in 1982 (Dybwad, 1997).

In Britain most self-advocacy initiatives took place in services. An early example is the survey of views of users carried out by Wandsworth Council in 1974 (Williams and Shoultz, 1982). Work in the late 1970s in day centres uncovered the phenomenon of user committees (Whelan and Speke, 1979). In 1980, Crawley carried out a national survey of all day centres (1983). She found that 22% of centres had committees, mainly concerned with centre issues such as dining arrangements and toilets.

During the 1980s, there was a rapid expansion of user and self-advocacy movements, fighting against poor quality services and arguing that people should be enabled to take control for themselves (Beresford and Croft, 1993; for examples of initiatives, see Beresford and Harding, 1993). The learning difficulty model of self-advocacy developed at the same time as similar movements among other groups, such as people with mental distress (Survivors Speak Out, 1988) and older people (Dunning, 1995).

In 1986-7 Crawley repeated her survey (1988) and found that the percentage of centres with committees had increased to 60%, while there were also some groups in hospitals (27%). While most still discussed centre-based questions, there was now discussion of policy,
staffing, and issues such as labelling. Achievements were recorded in the majority of cases, such as changes in service practice and personal developments for the people with learning difficulties.

Wertheimer describes the advent of an independent People First in 1984 as a turning point (1990). Organisations such as the King's Fund and CMH provided vital financial and practical support to these early developments. People First London encouraged the formation of other groups and linked them together (King's Fund, 1985). Ideas have been disseminated through newsletters, conferences and workshops (e.g. People First, 1994; Pippet, 1990; Wertheimer, 1990). There are now national People First organisations in Ireland, Wales and Scotland. There have been attempts to set up an England People First, and now initiatives to launch People First UK (Holman, 1997). An indication of the maturity of the movement is that People First London is able to admit to difficulties and to learning from a problematic year (People First London, 1997).

Developments in self-advocacy took place as part of an important progression in the campaigns for people with learning difficulties to have an ordinary life. The role of CMH in learning lessons from others, particularly the USA, and encouraging developments here (e.g. Thomas et al, 1978; Wertheimer, 1986), has been complemented by the initiatives of the King's Fund. In particular, the publication An Ordinary Life in 1980, had a profound effect on the thinking of many health and social services departments (Whittaker, 1996). The key was aiming for people with learning difficulties to move 'in the mainstream of life', which included 'the same range of choices as any citizen' (King's Fund, 1982, p.8). This was followed by An
*Ordinary Working Life* (King's Fund, 1984) and *Ties and Connections* (Tyne, 1988) making the same demands for people's day-times and relationships.

As People First London celebrate their 14th birthday in 1998, they can boast a victorious battle for charitable status, establishment as a limited company, and many specific projects, for example on sexuality, civil rights and accessible information (Sex and Relationships Project, undated; People First London, undated b and c). In addition, there is service-related work: complaints, assessment, housing, social work training and evaluations (People First, 1994, undated a and b; People First London, 1994c and undated a; Whittaker *et al.*, 1991).

At this stage, self-advocacy tends to dominated by white men (Walmsley and Downer, 1997). There has been some attention within People First to the interests of specific groups: women, black people, people with Downs Syndrome and young people (Walmsley, 1993 a; Women First, undated; Black People First, 1994; Johnson, 1997; People First, 1995; Young People First, 1994). Outside People First there are specific initiatives such as the Black Friendly Group (Walmsley and Downer, 1997) and the Powerhouse, a group organising against abuse (The Powerhouse, 1996).

A later development in self-advocacy was advocacy projects, for example, Learning Disability Manchester Advocacy Project (Manchester People First and LD-MAP, 1997). These are mainly independent projects, though often with finance and support from services. In 1993 Sutcliffe and Simons drew a picture of self-advocacy developments. They reported a range of initiatives, from user committees in services, to women's groups, groups for black people, campaigning groups and independent advocacy projects. Aims and achievements of self-
advocacy groups are recorded in a number of their own publications (e.g. Kidderminster First, 1989; Manchester People First, 1994; People First Wales, 1996) and reports of events at which groups have spoken on their progress (e.g. Whittaker, 1991). There are efforts to involve people with more complex disabilities (Whittaker, 1993). There are now generic projects developing, joining together different forms of advocacy and different groups of people (e.g. Fairdeal, 1996).

Self-advocacy by people with learning difficulties does not stand alone. Brandon et al (1995) examine seven types of advocacy: professional, service professional, advocacy by families, self-advocacy, citizen advocacy, peer and collective advocacy. Citizen advocacy is the most developed. It grew out of normalisation and the perceived need to protect highly vulnerable people. This is a form of advocacy involving the partnership of a non-disabled person with a person with learning difficulties. Citizen advocacy began in the 1960s, based on principles set by Wolfensberger and O'Brien (Advocacy Alliance, 1985). The principles underline a need for a long-term relationship. Many projects have grown up tied to these principles and resisting any deviation. However, Simons (1993b) argues for a midway between rigidity and abandoning values. This tendency is breaking down as some projects develop new methods (such as short-term relationships) and link with self-advocacy (Giles, 1996).

Another important dimension to the self-advocacy movement has been personal testimonies. The recording of life stories is an activity which echoes the movements of other oppressed groups, in which the histories of people who have traditionally been written about in terms of the dominant ideology in society have been rewritten by those people themselves (e.g. Bryan et al, 1985). Important landmarks in personal stories were _The World of Nigel Hunt_ by Nigel
Hunt in 1966 and *Tongue-Tied* by Joseph Deacon in 1974. The tradition has continued, for example, with the publication of Edie Wildey's story (1987), an anthology of life stories and views (Atkinson and Williams, 1990) and the recording of people's experiences of institutions and community care (Atkinson, 1993).

Self-advocacy has undoubtedly been difficult for families. Whittaker (1996) explains that many parents saw the new moves as threatening, but she also knew parents who welcomed self-advocacy as something they had always wished for. A study day in 1979, held by Parents for Children and the King's Fund, agreed that young people with learning difficulties should have the same rights and choices as their siblings, and recommended an advocacy scheme be set up to help people get their rights and take on responsibilities (King Edward's Hospital Fund for London, 1980). Mencap established a Participation Forum (*Parents Voice*, 1983).

Some advocacy projects have tried to involve parents in the groups to overcome fears (Shoutz, 1994), and others have made an effort to explain self-advocacy to parents (Dawson and Palmer, 1994). However, despite these efforts, and despite the evident broad meaning of self-advocacy, I have found few mentions of families in the self-advocacy literature.

It is here that the oppression of people with learning difficulties becomes important. One of the most significant aspects of life for the majority of people with learning difficulties is the service system, from national policy to local services to front-line workers. I have already discussed the power services have in the lives of people with learning difficulties. As self-advocacy has developed, so has the interest of service workers. Staff have become aware of the need to help their users develop choice-making skills (University of Southampton, 1994) and self-esteem (Mosley, 1994). Enlightened workers have set up self-advocacy groups, often
calling them People First to ally to that movement, but in fact still service-based. Service
workers have maintained a significant influence as the channel through which information
passes to groups. All of this, although well-intentioned, has lead to such a burgeoning interest
in user involvement that other aspects of self-advocacy have been put in the shade.

When the King’s Fund Information Exchange on self-advocacy devoted an issue to
achievements, all the contributions from different self-advocacy groups were about changes in
services (Whittaker, 1992). Individual Planning (e.g. Sweeney, 1991), Shared Action
Planning (Brechin and Swain, 1988) and Personal Futures Planning (Greasley, 1995) are
opportunities by which people can achieve control and have led to attempts to help people get
real control in some areas. Service brokerage is another development aiming to place the user
in a position to control the finances and buy their own services, with the help of a personal
support network (Brandon and Towe, 1989). Elements of this idea can be found in the Direct
Payments legislation now allowing people to purchase their own services (Kestenbaum,
1996).

Self-advocacy groups are involved in staff recruitment, training and consultation (e.g.
Townsley and Macadam, 1996; Harding, 1995; People First Wales, 1996), while others
discuss policy issues such as education, employment, wages, transport, and housing (Brown,
1992). The precedent for evaluating services was set by People First London (Whittaker et al.,
1991). Now groups up and down the country take part in such research (such as the
collection of examples by Whittaker, 1997). However, despite all these examples, Simons
(1993c) found that many people in service-based groups felt that they did not have much
power. Development is isolated and patchy.
It is important to be clear that self-advocacy and user involvement are not the same thing.
User involvement can be part of self-advocacy, and for many people it is clearly central to it.
But people with learning difficulties are not users of services all the time - some are not users
at all - and self-advocacy is, as has been seen, about something much wider. Barnes and
Shardlow (1996) point out that even groups in services have objectives beyond a narrow
service focus. Self-advocacy and user involvement are too often seen as synonymous,
providing a way of services controlling self-advocacy.

Not all service interest has been benevolent. Some staff may be fearful of self-advocacy:
Crawley describes 'the feeling of loss of control and the subsequent fears that everything will
go disastrously wrong' (1990, p.103). Brown believes that there is too much 'smug
dishonesty: professionals feeling good because they are enlightened and radical enough to
"listen" to the service users' (1987, p.2). Brandon makes a similar point, fearing that self-
adovcacy does nothing more than make oppression feel slightly better. Just tinkering with a
day centre, for example, when people really want a job and a living wage, 'is simply putting
velvet on the existing handcuffs' (Brandon, 1988, p.2).

Dowson's important book Keeping it Safe (1990) was a warning that self-advocacy is 'fast
becoming no more than an accessory for fashion-conscious services', where professionals are
'trivialising and neutralising' what could otherwise be an important movement with great
potential for change (p.2). He looks at a number of ways in which services can hold on to
power. Self-advocacy is given a slot in the timetable, with services choosing when it happens
and who goes, putting people in self-advocacy groups because it will be good for them, or
taking them out as punishment. Self-advocacy is deemed to require training first. The service
sets the rules, controls the information, and decides where the self-advocacy group has a role. A more overt way in which services try to control self-advocacy is by direct challenge - 'you can only speak for yourself, you're not representative'. Yet as Harrison (1993) and Beresford and Campbell (1994) have pointed out, many users actively attempt to consult and elect spokespeople.

Aspis (1997) argues that the skills taught to people with learning difficulties do not equip them to gain effective change. They rely on communication skills and the promotion of moral rights which are not backed up by law, rather than campaigning skills and knowledge about power structures. She argues that this means that the achievements of self-advocacy are largely cosmetic and reliant on goodwill. As one respondent said to Simons (1993c): 'It's kiss the bosses'.

The advent of community care legislation has given a new impetus to service providers and purchasers to seek the views of users. The Social Services Inspectorate said of the 1990 NHS and Community Care Act, 'The rationale for this reorganisation is the empowerment of users and carers' (Social Services Inspectorate, 1991). However, as pointed out by many writers (e.g. Barnes and Wistow, 1992; Hasler, 1994; Philpot, 1993), the legislation does not promote user-led, user-run services. What was introduced were market principles - users become consumers and speak up in that capacity. Unlike the conditions that led to the 1971 White Paper, the 1970s onwards have seen economic recession and successive cuts in welfare spending. The political ideology behind the legislation is expansion of the private sector and individual responsibility.
Wistow argues that the rhetoric of choice has not been matched by reality:

'The promotion of choice and independence is inextricably bound up with funding adequacy. Choice is limited by the range and level of services available and the access to independent living options is restricted by cost ceilings placed on domiciliary care packages.' (1994, p.9)

The contract culture has led to a fragmentation of provision of services. Mencap describes community care as Britain's Other Lottery (Singh, 1995). Consultation has marginalised people with learning difficulties (Bewley and Glendinning, 1994). The spirit of choice and an ordinary life are still being pushed by organisations such as VIA and the King's Fund, both in residential services (Collins, 1992; Kinsella, 1993) and day services (Wertheimer, 1996).

The 1980s saw a shift in political ideology and social policy, with an emphasis from the New Right on privatisation and consumer voice, rather than local authority provision and collectivity. This shift has encouraged a dual approach to user involvement (Croft and Beresford, 1990; Beresford and Croft, 1993). There is the consumerist approach, built into legislation, couched in terms of market preferences and the right to exit if you do not like it. Then there is the empowerment approach, concerned with collectivity and rights, and with change in the whole of life. These contrasting approaches are highlighted by, for example, Taylor et al (1995) and Barnes and Walker (1996). The government, through service managers and purchasers, thus emphasises the individual's relationship with the service, because of both the individual model of disability and the need to dilute opposition. However, attempts to influence services individually will always be limited. Individuals can be persuaded, ignored and divided off against each other. Collectively, people have strength, can maintain a consciousness of what others want as well as themselves, and can tackle broader issues. From the discussion so far, it is clear that the collective element to self-advocacy is vital as far as those involved are concerned.
One undoubted result of the community care reforms, however, is that services now have to consult their users. Simons warned in 1992 of the risk that services would ignore the way people already speak up and substitute their own mechanisms, and that services could supply resources as a way of cutting across independence (1992b). George (1995) gives an example of an authority setting up a user bureau when there was already a user group. Stalker found, in her case study of a service-based Members' Council (1997), issues of power and control, with parameters to choice-making set by the service. Contracting has raised levels of control over independent advocacy projects, with service agreements tying the project aims to service interests. One project explains this reality:

"On several occasions it has been said by decision-makers "Why fund an organisation that only makes our life more difficult?"... Several advocacy projects have recently been "told off" for carrying out advocacy work in areas of "political sensitivity" like budget cuts, eligibility criteria and "normal limits"."  
(Fairdeal, 1996, p.11)

People with learning difficulties are in an anomalous position. The fact of their oppression means that they are often unable to get started without support. Drake (1997) suggests three roles for non-disabled supporters of the disability movement: exposing, through research, the disabling aspects of society; supplying resources; and responding to requests for help. I suggest that people with learning difficulties will often also need someone to introduce ideas and facilitate the beginnings of self-advocacy.

A crucial role is that of the adviser, the usually non-disabled facilitator of a self-advocacy group. Worrell (1988) and Dowson and Whittaker (1993) have written advice for advisers. Advisers are often volunteers, or employees of independent advocacy schemes - such are the advisers to groups in Manchester, for example (Manchester People First and LD-MAP,
Advisers may have learning difficulties themselves and be supported by a non-disabled co-worker, such as those employed by People First London. Many advisers, however, are service workers. People with learning difficulties have expressed the need for advisers to be independent:

"...the adviser needs to be someone who is always on the group's side - someone they can trust. This will be very difficult if the adviser is not independent and has to answer to some higher authority who also have control over group members'. (Dowson and Whittaker, 1993, p.14)

In short, advisers, 'in giving help, are also best placed to act as agents of control on behalf of the service system' (ibid., p2).

The role of advisers is very little researched (Walmsley, 1997). Goodley (in press) carried out an ethnographic study of four self-advocacy groups. He found no 'good' and 'bad' advisers, and argues against assumptions about advisers' abilities to support a group based only on their structural position (staff role = bad adviser). Stalker's case study of a self-advocacy group (1997) tends more to emphasise the influence of a service setting. Dowson and Whittaker point out that on the whole advisers believe in self-advocacy. The problem, according to Goodley (1997), centres around the understanding of disability espoused by the adviser. This applies to service-based and independent advisers alike. He contends that it is the dominant individual model that threatens to stifle self-advocacy, which would be better practised from the social model position.

This is without doubt true. An adviser coming from the individual model will support the right of people to have their views heard, but will ultimately see the problems people face as coming from their impairment, and that their achievement will only be able to go so far. Self-advocacy practised from the social model position would see problems as resulting from
material conditions, funding, poverty, support-levels etc., and would help people to fight for better conditions. A self-advocacy movement rooted in the social model would be more able to withstand efforts of services to control it and more effective as an agent against oppression. But this is the nub of the problem: the oppression of people with learning difficulties is such that they do not always have sufficient control of their groups or access to debates about theory and strategy. (Research into how much self-advocacy activists are actually aware of such ideas as disability theory would be interesting.) The work of Stalker (1997) suggests that even a skilled independent adviser cannot overcome the influence of the service.

Aspis argues that self-advocacy has become 'a tool to support people with learning difficulties to accept their position in society', to 'accept the best out of a bad deal' (1997, p.653). Self-advocacy is, in her view, 'modelled on the internalised oppression of people with learning difficulties' (p.653). This is an important allegation from a self-advocacy activist.

Self-advocacy is full of contradictions. Much of current practice is influenced by the individual model of disability, as it takes place in a service system and society which still largely operates on that model. The oppression of people with learning difficulties is such that even their own movement is in large part in the hands of others. However, much of the support offered to self-advocacy is genuinely rooted in a wish to empower people with learning difficulties, and (if not yet consciously) advisers and others are groping towards a social understanding of disability. The oppression faced by people with learning difficulties means they need the strength of others in the same fight: self-advocacy supporters, the wider disability movement and service workers in their organisations.
People with learning difficulties are a highly oppressed group, whose experiences are made more complex by the reality of impairments which make it easier to both justify and perpetuate oppression. The social identity of people with learning difficulties is characterised by a deeply-ingrained perceived need for them to be cared for and controlled. Integral to this process and part of its justification is infantilisation. Self-advocacy, on the other hand, claims autonomy and adulthood. It thus challenges the popular identity of people with learning difficulties. I have shown, however, in the discussion of the development of self-advocacy, that the oppression of people with learning difficulties is such that even self-advocacy is itself vulnerable to the power of services and the interests of social control.

This chapter has indicated that most attention in the self-advocacy literature has been paid to influencing services. The development of self advocacy has been subject to influences which have pulled it in a service orientation. Nevertheless, the meanings of self-advocacy for people with learning difficulties clearly point to self-advocacy being about the whole of life, which therefore includes families.

I have shown that there are significant gaps in the literature reviewed in this chapter. The application of the social model of disability to people with learning difficulties is still new. Though begun ten years ago, there is only a little discussion (e.g. Williams, 1989; Chappell, 1992; Walmsley, 1994), and a small amount of work applying the model to particular areas (e.g. Chappell, 1994, on friendship; Goodley, 1997, on self-advocacy). This thesis makes a contribution to the application of the social model to people with learning difficulties.
There is particularly a lack of theorising about self-advocacy itself. The self-advocacy literature is overwhelmingly in the manner of reports, manuals, examples of practice and ideas for skills development. Exceptions are the warnings made by, for example, Aspis (1997) and Dowson (1990). Academic interest in analysing self-advocacy is fairly unusual. Writers from different perspectives have argued for self-advocacy to be understood as part of normalisation (e.g. Crawley, 1988), a route towards citizenship (e.g. Barnes and Shardlow, 1996), a mechanism for user involvement in services, especially in line with community care (e.g. Jack, 1995), and a movement to fight against oppression (e.g. Williams, 1989). Self-advocacy is put forward as a possible strategy for change but the discussion rarely goes beyond that to analyse self-advocacy itself. Notable exceptions are Walmsley and Downer's discussion of the possibilities for self-advocacy to incorporate diversity of identity (1997); and Goodley's application of the social model to self-advocacy (1997), arguing that for it to be effective it needs to be practised from this perspective rather than from the individual model. This thesis is an important contribution to the new theoretical discussion about self-advocacy.

Mostly clearly, there is an absence of analysis of the application of self-advocacy to families. I have so far only referred to the very small literature on this, to indicate the subject's neglect, and I discuss it in more detail in chapter 3. My investigation of self-advocacy and families is therefore a significant contribution to the literature on self-advocacy.

The next chapter continues the literature review, turning to the literature on families with people with learning difficulties and the transition to adulthood, and relating these to self-advocacy. It discusses the few studies of self-advocacy and families.
Chapter 3

LITERATURE REVIEW:

FAMILIES, ADULTHOOD AND SELF-ADVOCACY

1. Introduction

This chapter reviews the literature on families and the transition to adulthood, in order to understand the context for self-advocacy and families. The experiences of families are such that the reception for self-advocacy will be very ambiguous. I argue that self-advocacy, in its claims to autonomy and adulthood, challenges much of the basis of families with adults with learning difficulties.

I first consider how the concepts of care and control apply to families. Feminist approaches to the family are discussed within section 2. I argue that there is an expectation on families that they will both care for and control their adult children with learning difficulties. The chapter then reviews the literature on families. Within the general family literature there is an absence of families with disabled members, and of families in which children stay at home into adulthood. However, there are concepts and models which are of use in understanding families, and these are applied.

I examine the extensive separate literature on families with members with learning difficulties. This includes pathological approaches based on the individual model of disability, and more
rounded approaches. I again locate my analysis in the social model of disability. The viewpoints of people with learning difficulties are shown to be largely missing.

The transition to adulthood is explored, including a wider discussion of identity. Adulthood is a problematic concept for people with learning difficulties. The centrality of adulthood in self-advocacy and its relationship to families is discussed. I argue that adulthood is a social construction, made more problematic by the oppression of people with learning difficulties.

2. Care and control in families

This section analyses families in order to shed some light on the literature that follows. The social construction of disability and dependency was established in chapter 2. I also discussed the dual idea that people with learning difficulties need both care and control. This section applies these ideas to families. My argument is that the expectation on families is to both care for and control their adult sons and daughters with learning difficulties.

Even at the height of institutionalisation, most children and adults with learning difficulties continued to live with their families (as shown by, for example, Bayley, 1973). The family is a complex institution with various roles, including loving, intimate and protective relationships, nurture and preparation for future life. Nevertheless, the family is also a social and economic institution, with functions which preserve social order. One of these primary functions is care. It is seen as the natural, integral function of families, to care in a loving relationship for children and dependent relatives (Dalley, 1996).
Most people enter into a relationship because they care about somebody, and have children about whom they also care a great deal. In the family, the difference between caring about someone and caring for someone (i.e. carrying out practical tasks, or 'tending') is blurred (Parker, 1981). Caring is portrayed as "natural", worthy but unremarkable, so that the act of not caring would be seen as a defection from normal loving relationships' (Brown and Smith, 1993, p.186). In this way, family care produces and nurtures the next generation, and looks after all those people who are considered by the capitalist mode of production to be unable to work and unable to look after themselves, i.e. those who are old, ill or impaired.

Feminist debate about care, in particular community care, is very important in dismantling the idealised version of the family. The 1970s distinction care in the community and care by the community originally meant a distinction between formal service settings and a fuller degree of integration (Bayley, 1973). In the economic and political climate of the 1980s, this became a distinction between formal care and 'informal' care in the home. Dalley (1983) argues that community care rests on a rosy image of the family, side-stepping the oppressive realities for many women. Women are the 'natural carers' - for men, care means being responsible for a person, not doing the physical caring himself (Dalley, 1996). In community care, women are assumed to be dependants of men, to be out of the labour market, or able to leave it, and available for caring duties at home.

Finch (1984a) believes that community care is inevitably sexist, and there should therefore be a return to some form of residential provision. Dalley argues for new forms of collectivity, not proposing a return to institutions but recalling the communal ideals of the early women's and socialist movements. She envisages a society based around group living, group concern and
ungendered roles, in which a disabled person would control her or his own life (1996).

Barrett and McIntosh also argue for collectivity, 'by building up all sorts of other ways of meeting people's needs, ways less volatile and inadequate than those based on the assumption that "blood is thicker than water"' (1991, p.159). This relates to the work of Finch and Mason (1993), who show that responsibilities in modern families are more likely to be negotiated and cannot be assumed.

Although making a vital contribution to the understanding of families and care, feminists have fallen into the trap of assuming dependence. Dalley (1996), though recognising the interdependence of human life, nevertheless seems to assume the dependence of disabled people. These ideas are countered by disabled women as oppressive. Keith argues:

'In wanting to show how difficult and unrecognised the work of the carer is, many have thought it necessary to portray those who may be in need of care as passive, feeble and demanding'. (1990, p.v)

Feminists have taken an 'us and them' approach (Morris, 1991), separating disabled women from 'women'. They overlook the fact that, for example, women with learning difficulties are oppressed as women, often being kept protected at home and having to take on caring roles themselves (Williams, 1992). Smith and Brown (1989) combine these points, describing the reality of care falling on the shoulders of women, but at the same time recognising the parallels between the oppression of women and of people with learning difficulties.

Thomas (1993) asserts that there is a need to reconstruct concepts of care. She argues against the characteristic feminist 'home-based kin-care' concept as too narrow, and argues for a comprehensive 'unified' concept to include a wider range of identities, domains and relationships. However, this concept is far from 'unified' because it assumes dependency and
allows for no possibility for the 'dependent' person themselves providing care. Walmsley (1993b) has demonstrated that some people with learning difficulties provide care to parents, and some are in mutually supportive, interdependent relationships. Thus, in place of the dichotomy between carer and cared for, Walmsley proposes a continuum of care.

Nevertheless, the popular conception of people with learning difficulties as dependent and in need of care remains. That this is so, despite the evident fact that they themselves are often carers, is partly due to the infantilisation of people with learning difficulties. This is shown in the statements made by Buck in the 1950s, a parent of an adult:

'...she had no burdens on her happy childish mind. Worry and anxiety would never touch her... I am glad she has remained a real child.' (1951, p.22)

Nevertheless, parents' own experiences will often show them that their children do grow up. Grant describes her son at 18:

'Along with the razor came adolescence. Suddenly he was a young man. Instead of Peter Pan he took on the persona of Adrian Mole - developed spots and fell in love, madly. Clothes were of real interest, especially waistcoats, and aftershave became a necessity.' (1995, p.15)

Thus there are counter-pressure to the notion of people with learning difficulties needing constant care and protection. Dependency is countered by their caring roles; infantilisation by the physical facts of growth. But in addition to the caring role there is the conception of people with learning difficulties needing control. Again, this has been discussed in chapter 2, and needs now to be applied to families.

The role of the family in social control has long been recognised. Engels explained the origins of the family in the development of private property and classes, as a unit through which private ownership and economic activity were organised (Engels, 1972). Protection of
property and maintenance of order became functions of the family. For example, in Roman society, the head of the household had the power of physical chastisement and even of life and death over all the members of his household. 'From its origins violence and coercion were built into the family as a social institution' (Creear, undated). Today's family is obviously far-removed from the Roman household, but the control role lingers on, both in our legislation and in ideology (Gittens, 1993).

The right to beat wives was enshrined in British law till 1896; in 1959 a judge stated that it was not a crime to punish a wife as 'one punishes a naughty child' (Campaign Against Domestic Violence, undated, p.3). The cultural expectations that the family should control children can be seen in the popular defence of smacking and in the moral outrage and scapegoating of families, especially mothers, that follows youth crime.

In 'normal' families, the balance between care and control moves in the direction of independence (Brannen et al, 1994), when the care and control elements are assumed to end, or continue in a distanced form. There is very little written in the literature about what happens in families where the child continues in the family home into adulthood. But societal expectation is that people with learning difficulties need control and care into adulthood, and thus the functions of the family for children are continued into adulthood.

This discussion is important in understanding the reception for self-advocacy. The social meaning of learning difficulties is in terms of dependency, infantilisation, care and control, either in services or in families. Self-advocacy, in claiming autonomy and adulthood,
potentially challenges the very basis of adults with learning difficulties living with their families. The next section will examine the experiences and outlooks of families.

3. Families' experiences and outlooks

This section addresses the literature on families. The general literature overlooks disabled people, while that on families with people with learning difficulties has traditionally come from an individual, pathological perspective. There is thus a sense in which families with people with learning difficulties are set apart from the norm. This approach disallows a full understanding of self-advocacy in the family. A more rounded approach to families better helps to understand the conditioning and experiences which impact on the experience of self-advocacy. This section also demonstrates that the perspective of people with learning difficulties is largely missing from the literature.

The mainstream literature on families mainly ignores the existence of families with disabled members, suggesting that such families are deemed to be outside the norm. Useful analyses, such as Smart (1997) on the changing nature of families, Finch and Mason (1993) on negotiation of responsibilities, and Brannen et al (1994) on adolescence and family models, all largely overlook disability. Harding (1996), on families and social policy, makes a brief contribution on community care, but based on the assumption that people with learning difficulties are dependent. Work on adolescence and adulthood tends also to ignore disabled people (e.g. Youniss and Smollar, 1985) and makes the general assumption that adults leave home. An exception is Morrow and Richards (1996), who investigate the experience of disabled youth achieving adulthood, within a broad study of all young people. They observe
that many young people (both disabled and non disabled) stay in the family into adulthood, with leaving home a protracted process.

There is, however, an extensive literature on families with children with learning difficulties, much of which tends to be of a pathological nature, reinforcing the notion of separateness. The 'official' literature on families is almost in its entirety from the perspective of mothers, and increasingly of siblings and fathers. There is little attention paid to the viewpoint of people with learning difficulties themselves. Two studies in the 1980s sought the viewpoint of people with learning difficulties on family life (Flynn and Saleem, 1986; Cattermole et al, 1988). These found social isolation and little financial autonomy; a lack of transfer of skills from services to home and an anxiety about the future. Walmsley's (1996) biographical interviews with 22 people with learning difficulties found views which challenge some of the stereotypes of family life, significantly regarding care and dependency. The people she interviewed did not accept that they were dependent and defined relationships as mutual.

For the most part, I have turned to the self-advocacy literature to find the perspective of people with learning difficulties on the family (see chapter 2). Direct reference is sparse, but groups (particularly independent groups) do take up a number of issues to do with families. The self-advocacy literature demonstrates ambiguous feelings. Inclusion International's committee of people with learning difficulties emphasise that:

'Our families are the most important people in our lives. They will always be there for us... Our families give us our identity or place in life. Without them life can be very difficult.'

(1996, p.19)

Nevertheless, people still want autonomy, and it is here that they experience difficulties. The commonest themes that arise centre around day-to-day control, being treated like a child,
independence and letting go (such as, Something to Say Project, 1987; Young Women's Group, undated; Cooper and Hersov, 1986).

Most material is from the perspective of parents, especially mothers. Research has focused on the negative impact on a family of having a child or adult with learning difficulties. Hirst (1985), Pahl and Quine (1987), Landis (1992) and Fujiura et al (1994) have examined the health, employment and financial costs, marital status and social isolation of mothers. Maternal reaction and stress have often been researched (Quine and Pahl, 1985; Singer and Irvin, 1989; Bainc et al, 1993; Oh et al, 1994; Courcell, 1996). Common themes are related to the son or daughter's behaviour, loss of sleep, isolation, money, multiplicity of disability and health. Though rarer, there has been study of the stress to fathers (Krauss, 1993) and of adverse effects on siblings (Gath, 1974). Kobe and Hammer (1994) undertook a study of depression in children with learning difficulties. This negativity is mediated by research into coping strategies (Williams, 1993; Beresford, 1996). For example, Margalit (1997) looked at resilience, family cohesion and adaptability.

Focusing on this evidence could lead to the conclusion that families are too worn down by constant and often unsupported care over years to worry about self-advocacy, and it is possible that for some this is the case. However, this traditional picture of burden and stress is constantly counteracted. Personal accounts (e.g. Hannam, 1975; McCormack, 1978) have shown the reality of the complicated and often 'normal' life of families with children with learning difficulties. Many stories stress the pleasures and gains, presenting a very different perspective from the traditional 'handicapped family' (e.g. Cole, 1993; Sapp, 1994; Bochenski,
The picture thus generated is one in which self-advocacy could be welcomed and encouraged.

This challenge to the studies focusing on negative factors is both valid and problematic. The interpretation behind much writing and research on families is a pathological one, i.e. that families with disabled members become themselves malfunctional. It has been argued that this interpretation denies 'the heterogeneity and normality of families' (Jefford, 1990, p.35). Many families with disabled members see themselves as just the same as any other. Many 'normal' families suffer stress, inadequate living conditions, unable to afford basic necessities, isolated and without decent childcare (see, for example, Cockett and Tripp, 1994).

I would argue that the problem with many such studies of burden is also that they tend to focus the problem of disability within the individual and the problem of coping within the family. The poor material conditions and stress levels are described as the impact of having a disabled child, and even levels of parental coping are sometimes ascribed to attributes of particular parents - the problem lies with the disability, and then with the family's inadequacy for not coping. The risk of countering this with stories of joy and survival is that the very real struggle faced by many families could appear to be glibly overlooked in an effort not to degrade the person with learning difficulties.

The only way to fully reconcile this is to place the responsibility for these conditions within society. The social model argues against an individualistic interpretation, placing the responsibility for the problems learning difficulties are supposed to create at the feet of the economic requirements and ideology of capitalist society. Thus the low living standards and...
social isolation found to be common amongst families with children with learning difficulties are due to society's inability and unwillingness to cope with its disabled members; the stress suffered is both the result of struggling in these conditions, with inadequate support to cope with difficult behaviour, sleepless nights etc.; and is also likely to stem from social expectations and ideologies about disability. Baxter and Cummins (1992) demonstrate the stress caused to parents by stigma. Todd and Shearn (1997) show how parents, fearing the effects of stigma on their children, make strenuous efforts to prevent them from learning about the labels applied to them.

Qualitative in-depth approaches have shown a complex picture of family life and conditions (Wertheimer, 1981; Richardson and Ritchie, 1986 and 1989; Hand et al, 1994). Additional perspectives have been added by, for example, fathers' perspectives (Hornby, 1992; Young and Roopnarine, 1994; Herbert, 1995; Ainge, 1995), siblings' stories (e.g. Clancy Smith, 1996) and Walmsley's exploration of the interdependence of care, already referred to above (1993b). Such an approach allows for a more rounded understanding of self-advocacy in families, placing the experience within the 'heterogeneity and normality' of all families, but appreciating the impact of specific conditions.

One of the principal factors affecting parents' outlook is the question of support. Studies have found that support networks change throughout life, but that the central character is almost always the mother. The particularly vulnerable periods, where support is often low, are when the person with learning difficulties is an adolescent and again when they are ageing (Grant, 1988 and 1993; McGrath and Grant, 1993). As a parent, Thurlow (1996) explains the need for support, including support from other parents.
Services have often played a negative role, particularly at the time of diagnosis, when parents may have been told the 'bad news', given inadequate information and poor prognoses.

Services are considered to be poor again at adolescence, part of the process of infantilisation. Todd and Shearn (1996a) found that services expect families to always need the same kind of support throughout their lives. They found respite services restrict parents' lives with fixed and short times, limiting their ability to work or develop outside interests. There are many stories of dissatisfaction with services (Pask, 1993), from parents who have had to struggle for everything (Sinfield, 1996), having their lives transformed by the process (White, 1996). Despite being thus forced into becoming experts, Wertheimer (1989) found parental expertise is not recognised by professionals and instead they are made scapegoats. Opportunities for parents to see their children develop and learn about new ideas are sparse. It is particularly the case that parents often feel they have been kept at arm's length, and cast in a villain mould (Simons, 1992a). Wertheimer (1989) found that shifts in service approaches tended to compromise parents - they were told one thing when their children were young and another when they are older. Parents may therefore feel defensive, confused or cynical about such ideas as self-advocacy.

The residential options to allow sons and daughters to leave home are shown to be highly significant in shaping parents' feelings and anxieties about independence (e.g. Richardson and Ritchie, 1986 and 1989; Sanctuary, 1984; Card, 1983). Older parents have been shown to be particularly anxious about future care (Wertheimer, 1981; Walsh, 1992). Prosser (1997), in a study of parents of people with learning difficulties over 40, found only 28% had concrete plans. Lehmann and Baker (1995) found that younger mothers had the same expectations for their disabled children as parents of non-disabled children, but emphasised the need for their
offspring to be supported. There are financial questions too - the poverty of parents unable to work because of care is often alleviated by the income their sons and daughters bring in. Thus insecurity about the future may be a factor in limiting parents' ability to plan for and encourage autonomy.

When the adult child with learning difficulties does not leave home, other issues are raised. Wertheimer (1989) found that emotional bonds were greater when someone stayed at home, especially for mothers. Richardson quotes a mother:

'You are at war all the time... There is the emotional side of you which loves your child dearly and you don't want to part with him. There is the other side, common sense, which says now is the time. If you love him, let him go. You are doing it for him. But there is the selfish side too, can I manage on my own? I am going to be so lonely...' (1989, p.9)

Wertheimer found many parents saw caring for their son or daughter as a 'job for life'. Todd and Shearn point to the reciprocal notions of 'eternal children' and 'perpetual parents' (1996b, p.380). They analyse parenting as a 'greedy institution' which devours the entire person and resents outside activities. There is an increased feeling among parents of being left behind (Shearn and Todd, 1994): as their peers' children leave home and they develop a new postparental lifestyle, the parents whose adult child stays at home continue with a restricted life, and lack spontaneity and wider interests.

In an analysis of parents' attitudes to respite care, Todd and Shearn (1996a) theorise that different parents have different frameworks: the captive and the captivated, those for whom respite emphases how abnormal their life is and how much they want to stop being a parent, and those for whom it reinforces how much they want to be parents - usually because their other life options are so diminished. Therefore, they argue, services should start by supporting
parents to be parents, but as they get older should support them to be *people* so that they can achieve transition. This seems particularly needed when the lives of many elderly people with learning difficulties and their parent(s) are examined. Walsh, for example, has shown how much more isolated and restricted life is for elderly parents (1992). This restriction is also the case for their adult children, especially women (Grant, 1986; Walmsley, 1993b). A problem with the captive and captivated framework is that it overlooks this aspect of interdependence. It is equally conceivable that there are captive and captivated people with learning difficulties - those who care for parents but want their own life, and those for whom caring for parents is a desirable adult life. Barron (1997), for example, found young disabled women seeking caring roles as confirmation of their womanhood.

Parents in all families find autonomy and independence difficult (Youniss and Smollar, 1985). Brannen *et al* (1994) use the concepts *individuation* and *connectedness*. Individuation is applied to families in the dominant western discourse of adolescence as a process of separation. Such families are those who value independence for their offspring. Connectedness is chiefly used to describe families whose origin is outside the UK, which value solidaristic relations rather than individual autonomy. It may be that this category of connectedness can be usefully applied to families with an adult son or daughter at home.

Winik *et al* (1985) found three types of family: *supportive*, in which parents would support their son or daughter's transition without over-protection; *dependent*, in which the adult child remained protected; and *conflict-ridden*, in which the tension was not resolved. Walmsley (1996) found families falling into Winik *et al*’s three categories, but also more complexity. She found an additional category of *mutually supportive* relationships, where help was proffered
on both sides; and also dependent relationships in which it was the parent who was
dependent. These concepts are useful, both in the adaptation to account for caring roles
provided by people with learning difficulties, and in that they allow for conflict and a blurring
of experience. Application of these frameworks can help to understand processes in families
with adult children still at home. They lead us into a discussion on the transition to adulthood,
which has been shown to be central in self-advocacy.

The discussion in this section indicates that parents in all families find speaking up, adulthood
and growing independence difficult. The reception for self-advocacy at home will be
complicated by the experiences of families, including factors such as support and emotional
bonds. Service provision will affect parents' views, including factors such as the prognoses
given, levels of support and information, the keeping of parents at arm's length, changes in
policy, lack of provision for the future. The important point is that families with learning
difficulties should not be stereotyped and are not a homogenous group - some may want to
keep control, others may be passionate fighters for independence, but most will have mixed
feelings about the ideas of self-advocacy, adulthood and independence.

4. The transition to adulthood

This section examines the question of adulthood. Chapter 2 demonstrated the centrality of
adulthood in self-advocacy and pointed out that this would have implications for families. The
argument presented in this section is that adulthood is a social construction, which for people
with learning difficulties is heavily influenced by the individual model of disability and the
particular oppression of people with learning difficulties. Notions of dependency, the 'need' to
control people with learning difficulties and the image of the eternal child, all make the
transition to adulthood particularly difficult. This makes the central place of adulthood in self-
advocacy especially important for families.

As with the literature on families, there is a separation between mainstream youth literature
and studies of disabled young people. Tisdall (1997) suggests that the literature on disabled
young people has tended to take an individualistic approach, more recently influenced by the
social model and examination of social barriers; mainstream literature has overlooked disabled
people as statistically small, and has also often left families out of the analysis. There has also
tended to be an emphasis on a transition from dependency to independence (Tisdall, 1997).
This excludes people with learning difficulties from the analysis, assuming the dependency of
disabled people and emphasising independence rather than autonomy.

Clare (1990) explains that becoming an adult is not just to do with getting older. In the
western world it means changes in at least four areas: personal autonomy, economic self-
sufficiency, citizenship, and new relationships outside the family of origin. Morrow and
Richards (1996) add to this the end of full-time education, parenthood and becoming an
independent consumer.

In these terms, the transition to adulthood of people with learning difficulties has been of
interest to researchers. Both Johnstone, who interviewed five young adults (1986), and Flynn
and Hirst, who interviewed 79 (1992), found a sense of isolation and a lack of personal
autonomy, but also that aspirations were much the same as those of other young people.
However, studies show that these aspirations do not necessarily come to fruition: there is a
lack of further educational and employment opportunities and a likelihood of continued residence with parents (Hirst, 1983 and 1984; May and Hughes, 1988a; Johnstone, 1986).

Hirst, in a postal survey of over 1,000 young people with learning difficulties, found that less than one in ten of the 75% who had daytime activities had employment, while 80% of the sample lived at home (1983). Thomson et al (1995) found young adults with Down's Syndrome had a limited range of leisure employment opportunities, and continued 'dependency' on parents.

Simply using markers such as employment and independent living is in itself a limited notion of adulthood. As the Centre for Educational Research and Innovation (CERI) reports on adulthood and disability suggest (1986 and 1988), when a broader view is taken such markers can be seen to be largely socially created. Having a job, being independent and leaving home are not life expectations in all societies. Within most cultures these have traditionally been male markers, with women being expected to maintain economically dependent and passive roles into adulthood. (This will be seen in chapter 9 in regard to one of my respondents, Fazila Begum.) Within the relatively recent history of Britain, working class children worked from very young ages and often had to fend for themselves.

Today, with a million young people unemployed and tens of thousands homeless, such aspirations as getting a job and your own place to live are not achievable for vast numbers of youth (May and Hughes, 1988b). Morrow and Richards (1996) argue that economic and social changes over the past two decades (such as increasing numbers of young people staying in education, housing shortages, increased poverty, low pay, job insecurity, reduced
benefits, and government strategy to make parents responsible for their children for longer) have combined to make more problematic the transition to adulthood for all young people.

Legal thresholds are another marker of adulthood, which though technically applicable to people with learning difficulties, are still problematic. Few people with learning difficulties exercise their right to vote, for example (Ward, 1987), and may face social barriers in gaining access to adult entertainment (Hudson, 1988). Chappell (1994), for example, discusses the financial restraints which militate against people with learning difficulties going out socially and thus cultivating adult relationships. Walmsley (1991a) argues that there many socio-structural and ideological barriers to people with learning difficulties attaining citizenship.

Autonomy is a measure of adulthood that has been discussed in chapter 2. The Further Education Unit (1991) suggests personal autonomy as a main indicator of adulthood. Flynn and Hirst (1992) investigated autonomy for young people with learning difficulties living at home. They found that approximately a third lacked personal autonomy, for example, control over money, the ability to go out and privacy. Gender was significant in their findings, in that they found that women had less autonomy than men. Flynn and Hirst also found that autonomy decreased with increasing severity of impairment. I shall comment on these findings in relation to my respondents in chapter 8.

There is also the question of social expectation. Jenkins found that long-term unemployment does not prevent young people from becoming adults, partly because parents and children want it:

'Adulthood in Britain is a robust, if imprecise identity, of which people can only be deprived by circumstances that undermine its central portfolio of rights and obligations.' (1989, p.102)
It is likely that by this measure many people with learning difficulties will find they are not seen as adults. Attitudes which link disability to dependence and the idea of the eternal child will make the transition to adulthood more difficult. I have already shown that the ideology which has dominated service provision and popular conception has promoted the dual idea that people with learning difficulties need to be controlled as unable to control themselves and cared for as dependants. It has been shown that medical models, law and popular conception keep people with learning difficulties the eternal child. Negative and childlike images are maintained, for example, through popular media (Wertheimer, 1988b) and through use of mental ages. The very notion of learning difficulties is the opposite of adulthood. This denial of adulthood reflects and reinforces inferior social status, similar to the way in which black men were referred to by colonialists as 'boy', or women are referred to as 'girl'.

Youriss and Smollar (1985) argue that families play an important role in the transition to adulthood. They see parents and adolescents in alliance, with parents providing guidance and discussion as well as rules. Barnes (1997) argues that there are dangers in assuming a conflictual relationship between people with learning difficulties and their parents, and that parents can play an important role in empowering their sons and daughters. But given the experiences of many parents of people with learning difficulties, it is not surprising that they may not always do this. Unlike parents of other children, they may not only have to initiate and foster independence, but also have to deal with (in)adequacy of services, (un)availability of education and employment, and fear of social and physical risks (Clare, 1990).

Factors such as prognoses given early in a child's life and continued personal care will influence perceptions of status. As found by Wertheimer (1989), treatment at the hands of
services and society will impact on the parents' ability to view their child as an adult. Cooper and Hersov (1986) talked with parents who explained how they found thinking of their son or daughter as an adult difficult as they had always 'mollycoddled' them since childhood. Todd and Shearn found that parents felt their offspring could not be easily categorised and held ambiguous views of their status. For some this centred around the amount of care their adult children required, or their behaviour, being 'too young in their ways' (1997, p.349).

There are, of course, varied parenting styles in all families. For example, White and Woollett (1992) suggest three main kinds of parenting styles: authoritarian, which demands obedience; permissive, in which parents make few efforts to control; and authoritative, which encourages children to gain autonomy while also offering guidance. Similarly, Brannen et al (1994) suggest two variants of the transition to adulthood: when the young person is freed from parental guidance to achieve adulthood; and when parents prescribe the new responsibilities and status, and adulthood is ascribed. Though Brannen et al use these concepts to analyse families from different ethnic and cultural backgrounds, the concepts may be useful to help explain what happens to young people with learning difficulties. The preceding discussion suggests that adult status may have to be ascribed - and that in many instances it is not.

Adulthood can also be seen to have a personal, psychological aspect, a point made by Williams and Walmsley (1990). Whether or not a person is an adult depends to an extent on how they perceive themselves. Socialisation of a child with learning difficulties could have the result of that child not learning adult skills and behaviours and not even expecting to become an adult. The 1988 CERI report considers that accumulated self-images create an individual's
identity, and that becoming an adult is strongly linked to maintaining a continual positive sense of self. Holman (1981) believes that many young adults with learning difficulties slip back and forth between adulthood and childhood because of the lack of day-to-day experiences that reinforce adulthood. Establishment of identity through peer groups will be difficult for young people whose social lives are isolated and whose friends are also restricted in their transition (Atkinson and Ward, 1987).

However, this has to be understood dialectically. There is evidence to suggest that many people with learning difficulties develop positive self-images despite the attitudes of others (Jahoda et al., 1989). Bogdan and Taylor (1976) saw people in institutions actively making sense of themselves despite their circumstances. It is clearly the case that the people with learning difficulties who demand to be treated as adults view themselves as such even if others do not. The self-advocacy literature has demonstrated the demand to 'accept that we are adults' (Inclusion International, 1996, p.19).

It is useful at this stage to discuss the wider question of identity. It has been established that people with learning difficulties are seen as children, in need of care and control. The claim to adulthood is therefore in contradiction to everything that learning difficulty represents. There may be an argument that in claiming adulthood people with learning difficulties are trying to pass for normal or are even in denial of their own circumstances.

Goffman (1968) explained the process that takes place in the interaction between a disabled person and other people as stigma. Stigma is socially produced, the label society attaches to a person, which then reinforces deviance in the eyes of others. Goffman has been criticised from
a materialist perspective (for example, Finkelstein, 1980) because he takes disability as given, rather than socially produced itself. Additionally, the experience of disability does not come simply through the interaction with others but from material conditions and the structure of society. Nevertheless, stigma is a useful concept, in describing the interactions between disabled and non-disabled people, if not explaining how they come about.

Goffman argued that disabled people internalise stigma. He described their lives as craving acceptance and struggling to pass for normal. Stone (1995) points out the massive pressure, especially on women, to be 'normal' and bodily perfect. However, she asserts that this process inadvertently increases the oppression of disabled people by accepting impairment as negative. As Corbett (1994) says, it leaves the individual isolated in her or his experience.

Other people can reinforce this process. Abberley (1987) argues against the 'really normal' ideology of many well-meaning people, which says, 'to me you're normal'. This denies the reality of impairment and experience of disadvantage. The theory and practice of normalisation is based on these ideas (Chappell, 1992) and reinforces the notion that to be with impaired people is devaluing.

The problem with Goffman's idea of passing is that it assumes people are necessarily victims of the process. While it may be true that many people do struggle to 'be normal', there are other strategies people employ to deal with stigma. I suggest that for many people with learning difficulties there is not the option of 'passing'. Being segregated in hostels, group homes and day centres, always being accompanied by staff or parents, marks them out in such a way that they could not hope to pass. Edgerton used the concept 'denial' to explain the
strategy employed by people with learning difficulties he met in institutions (1993). In a sense this is 'deep' passing - rejecting a label and striving to be seen as normal despite all evidence to the contrary.

Bogdan and Taylor, however, argue that rather than being in denial, these people were renegotiating their identities:

'It is not that they don't see their situation as it really is. They have a different view of it from those who have judged them - they have a "truth" generated from a different place in the service system.' (1982, p.217)

I would argue that this is much more a possibility. Todd and Shearn (1997) found that the parents they interviewed strove to protect their sons and daughters from knowing their social identity. Parents are 'keepers of secrets', keeping their children in a 'protected capsule'. This does not prevent them from experiencing the effects of the label, of course. Souza (1997) describes awareness from a young age, not of her particular label, but of being treated differently. Davies and Jenkins (1997) confirm this, finding that the people with learning difficulties they interviewed formed their self-identity from experience more often than from discourse, because their parents tried to protect them.

This would suggest that rejection of labels and claiming normality is not conscious passing or denial, but is a response to the experiences people face. They may or may not be aware of the labels that apply to them, but they may see other people having the labels applied and not like what they see; they may know they get different treatment from others and want to be treated the same as everyone else.
Of course, many people with learning difficulties are conscious of the labels applied. Self-advocacy is one way in which people become conscious of the label of learning difficulties. Once conscious, again there are other strategies. One employed by the self-advocacy movement has been to campaign against labelling. Anchorage Self-Advocacy Group (1990) describe how they fought labelling. People First has campaigned consistently against 'mental handicap' in favour of 'learning difficulties', and continues to claim that term in preference to 'learning disability'. There is some validity in this approach. Attitudes do change over time (as is shown by Corbett and Ralph, 1996, for example) and different labels do lead to different reactions (Eayrs et al, 1993).

There is also a strong element of claiming normality within self-advocacy. As Souza explains:

'Nor am I mentally handicapped. The term seems to be saying there's a pretty little thing. I'm not a pretty little thing. I'm a valuable person in my own right. I have a lot to offer. I might have what the doctors call Down's Syndrome but I am a person first as is everybody else.' (1997, p.14)

This is not in the sense of passing, though, so much as Shakespeare's explanation (1996a): that people can internalise stigma and accept the identity society imposes, or can redefine themselves, develop a positive self-identity and go on to challenge exclusion and injustice. Souza is not in denial but is rejecting the identity society imposes on her.

Corbett links the disability movement to gay pride (1994), describing as 'coming out' the process of accepting the impairment, celebrating your identity with pride and combating oppression. There are some hints at this in the self-advocacy literature, for example, Dawson and Palmer (1993) use the term 'pride'. Walmsley and Downer (1997) believe self-advocacy is a way of celebrating difference. In claiming adulthood, people with learning difficulties are
perhaps redefining their identities, rejecting the child-like dependent identity in favour of autonomy, adulthood and 'normal' lives.

Adulthood is thus socially constructed. There is no fixed definition; adulthood changes over time and between societies. Walmsley's (1991b) study of the meaning people with learning difficulties attribute to adulthood found that while the concept was hard to grasp because of its abstractness, it generally meant independent living, managing your own money, getting married, having a home of your own, being treated 'right' and not being told what to do.

Other studies have shown the 'ordinariness' of people with learning difficulties' aspirations (May and Hughes, 1988a; Flynn and Hirst, 1992; Neumayer and Bleasdale, 1996).

It may be easier for women to achieve traditional adult roles than men. Women with learning difficulties can be expected to fulfil passive and caring roles in their adult lives, playing 'housewife' roles within group homes (Brown, 1994) and providing care for parents.

Walmsley (1993b) discusses the aspirations to care held by women with learning difficulties. There are of course conflicts within this. Morris explains:

'Disabled women... are considered to be unable to fulfil the role of homemaker, wife and mother, neither can they conform to the stereotype of femininity as it applies to physical appearance; yet, at the same time, the passivity and dependency which lies at the heart of disability as a social construct is certainly compatible with what it means to be a woman in our society.' (1993, p.88)

Women with learning difficulties may be carers of parents and of men, but are not supposed to be capable of caring for children (Booth and Booth, 1994).

I showed in chapter 2 the importance of adulthood in self-advocacy. Clare (1990), Centre for Educational Research and Innovation (CERI) (1986 and 1988), Flynn and Hirst (1992) and
Madden (1991) see self-advocacy as a route to addressing some of these issues. There is evidence that people encouraged to make choices develop a better self-image (Brown and Goldenberg, 1993). Crowley argues that, in her experience:

'...people were unable to be assertive about their needs if they had a negative self-picture and little awareness of their personal strengths. In turn, poor self-advocacy skills reinforced their low esteem.' (1995, p.8-9)

It is possible to see self-advocacy as having two dimensions here: a means of raising expectations, voicing aspirations, and getting help to achieve goals; and an end in itself.

Starting to make decisions and gradually gaining autonomy are part of the normal process of growing up. The parents who spoke to Cooper and Hersov (1986), Simons (1992a) and Wertheimer (1989), demonstrate the similarities between the struggles within these and all other families. Todd and Shearn say that 'adulthood is typically a contested identity, as young people experience difficulty in encouraging others to grant them this status' (1997, p.348).

This is not to suggest that people are not adults until they achieve self-advocacy, but to point out the similarities between the aspirations of all young people. Due to their specific conditions, it is the case that for many people with learning difficulties the opportunity to go through this process may not come till later in life and may never be completed. Self-advocacy is a challenge in two respects: it opposes the eternal child and claims adulthood; it opposes the notion of needing to be controlled and claims autonomy. However, the questions of control and oppression have important implications for the ability of self-advocacy to do this. I will now go on to examine the small amount of literature on this subject.
5. Self-advocacy and families - the literature

In this final section I look at the minimal literature investigating self-advocacy and families. The few studies which have addressed this area echo many of the points made in the discussion thus far, which influence the reception for self-advocacy. The studies are too small to make generalisations. What is significant, though, is that while there is not a hostile attitude from parents in these studies towards self-advocacy, there are few links made between self-advocacy and home, and levels of autonomy are still limited.

Most examinations of the relationship between self-advocacy and families have been elements of wider studies. Some have just sought the views of parents, for example, Webster's evaluation of North Manchester Self-Advocacy (1993), which talked to people with learning difficulties but not about families. Sutcliffe and Simons' book (1993), which brought together findings from the National Institute of Adult Continuing Education network with those from the Bristol Advocacy Project, and Cooper and Hersov (1986) sought the views of both people with learning difficulties and families. Simons (1992a and 1993a) asked members of self-advocacy groups about speaking up at home. The only study which concentrates on self-advocacy and families is Wertheimer's examination of the impact on parents when a young disabled person is involved in self-advocacy (1989).

The studies show parents' mixed feelings towards self-advocacy. Many acknowledged the benefits to their sons and daughters, seeing self-advocacy as important in their lives and recognising an increased assertiveness. They appreciated their children going to a place where they were accepted for what they could contribute and were proud of their achievements.
Some felt that self-advocacy did take place at home, and that by comparison choices at the
day centres were extremely limited. Other parents were sceptical about whether their son or
daughter understood their self-advocacy group. Sometimes parents did not recognise their
offspring's choices and got into conflict with staff, accusing them of 'twisting their arms
behind their backs'. Risk-taking was a tricky issue, which sometimes led to parents stopping
their sons' and daughters' attendance at the group.

This mixed picture is echoed by the views of people with learning difficulties in the studies.
Most had something positive to say about their families and some had achieved a degree of
privacy and independence within the home. But tensions were also identified; for example,
people were limited in what they were allowed to do and there were arguments about
personal relationships.

Simons (1992a) concluded that self-advocacy has had relatively little impact on home life. He
found little evidence of opposition from parents, but people with learning difficulties made
few links between their self-advocacy groups and home. There were many people
experienced in self-advocacy who hardly had any control at home and who appeared not to
see this as a problem. Wertheimer (1989) found that many parents still exercised great control
over their son or daughter, though sometimes with positive outcomes (for example, getting a
job for their son). Many also saw that their control could not be total. Wertheimer uses the
concept controlled independence to describe privacy and autonomy over buying clothes, for
example, which many parents allowed.
The impact of self-advocacy at home will be influenced by factors to do with the self-advocacy context and with families. Simons (1992a) thought three factors were operating in the self-advocacy context: some people saw self-advocacy as their affair, to be kept private; most self-advocacy activities were directed at services; and there was little direct contact between self-advocacy and parent organisations. Another factor could be isolation at home, away from the strength of a group. I suggest that the discussion in chapter 2 on the control over self-advocacy is crucial to understanding this situation.

Wertheimer (1989) considered the conditions and experience of families as a factor. She suggests that allowing people autonomy within the home is harder when there is continuing physical dependency. Routines are hard to change, and parents do more than they need to because it is quicker and easier, and because they often think no one can do it better. Some of her respondents admitted that their offspring were capable of more, but that old habits die hard. Privacy and confidentiality are difficult: Wertheimer suggests that as parents stay the main confidante, they may want to know everything and find not knowing a challenge. The discussion so far in this chapter, regarding the care and control functions of families, and issues of support, services and difficulties in the transition to adulthood, is instructive.

The gap in the literature regarding self-advocacy and families is huge, but the above studies tend to confirm the arguments presented in this literature review. The potential challenge of self-advocacy is against the assumed roles of people with learning difficulties in families of being dependent, like children, and in need of care and control. Self-advocacy is put forward by many writers as a route towards solving issues of autonomy, adulthood and oppression. These few studies, however, tantalisingly suggest that self-advocacy, in these cases, makes
little difference. This would seem to suggest a strong boundary between self-advocacy groups and families (Sibley, 1995, may be useful here in explaining the boundaries individuals and society construct). I suggest that the discussion in chapter 2 regarding the oppression of people with learning difficulties and the influence of services and professionals over self-advocacy, and the discussion in this chapter of the expectations and pressures on families, offer an explanation.

6. Conclusion

This chapter has demonstrated that societal expectation on families is that they need to care for and control their offspring with learning difficulties into adulthood, as if they were still children. Difficulties in the transition to adulthood are common among all young people, but it is particularly problematic for people with learning difficulties. I have argued that self-advocacy, in its claims to autonomy and adulthood, challenges the meaning society imposes on the identity of learning difficulties. It thereby has the potential to challenge much of the social basis for adults with learning difficulties living with their families. However, the experiences of families are such that the reception for self-advocacy will be very ambiguous. This, and the discussion about controls on self-advocacy in chapter 2, suggest limitations on the possibilities for self-advocacy at home.

The chapter has demonstrated gaps in the literature. There is a lack of interest within family theory in families with disabled members and families in which adults stay at home. While there are some useful models regarding family types and attainment of adulthood, there is a sense in which families with a person with learning difficulties are set apart. The literature on
adulthood focuses on routes and markers not commonly open to people with learning difficulties. Within the literature on families with people with learning difficulties there is only a little attention paid to the views of the people with learning difficulties themselves. The clearest gap is on the question central to this thesis of self-advocacy and families.

The chapter adds to knowledge about families in three ways: by drawing together family theory with what is known about families with people with learning difficulties, by illuminating the experience of families with adult children, and by highlighting the perspective of people with learning difficulties.

Having completed the literature review, the thesis will now discuss the methodology of my research.
Chapter 4

METHODOLOGY:

PARTICIPATORY AND QUALITATIVE

1. Introduction

This chapter addresses the dual but combined character of the methodology of this research: both participatory and qualitative. Participatory research is that in which people traditionally seen as subjects actively participate in the research production process (French, 1994). Quantitative work could be undertaken in a participatory project, but this chapter suggests that the same arguments point to both participatory and qualitative research.

One of the strengths of quantitative work is the ability to generalise and make predictions from results. However, my concern in this project was not to do that, but to discover subjective experiences, which could lead to stories with common threads. I considered a qualitative, in-depth, small-scale approach most appropriate. I also wanted my research to be participatory. My own practice in self-advocacy centred around helping people with learning difficulties attain more control in their lives. My newcomer's view of research was as just one more activity which impinges on a person's life, and which could have repercussions on the lives of several people depending on the implementation of its findings. It could not be so special an activity that it must be exempted from the same questions about control that I would apply to any other part of
someone's life. I wanted my research to be a shared endeavour, giving people the chance to evaluate their own efforts in self-advocacy.

This chapter discusses the theoretical basis for both participatory and qualitative approaches. The chapter begins with the theoretical framework for this thesis, from which methodology flows. I then turn to arguments which have helped to inform disability research. From positivism to feminist and other critiques, relationship-based and biographical approaches, I address arguments in social research: objectivity, partiality and power. I then discuss debates within disability research, including the question of participatory and/or emancipatory research. I support the central idea in participatory research of opening up the question, who can be a researcher? The discussion takes up the questions of the purpose and authority of research. The reality of intellectual impairment and the ability to carry out research is explored, and my conclusion is to suggest caution in assuming what people with learning difficulties can and cannot do. The compatibility of these ideas with academic requirements is discussed and I conclude that while emancipatory research does not rest easily in academia, there is much that researchers can do to make their work more participatory. (This discussion is developed further in the following chapter which explores my experience.) A key element in both qualitative and participatory research is reflexivity (Steier, 1991; Shakespeare et al, 1993), a process of scrutiny and reflection of ourselves as researchers, our respondents and our practice as an integral part of the work. This approach is discussed. The chapter closes by setting up a model for participatory research, which formed the basis for my practice.

As a thread running through and framing these arguments, I discuss the trends in learning difficulty research, which I briefly present here. The voices of people with learning difficulties are
the 'ultimate lost voices' (Atkinson, 1997). Learning difficulty research has tended to be medically-based and quantitative (as described by Digby, 1996, and Jackson, 1996), though there were exceptions in the 1960s and 1970s of ethnographic (Edgerton, 1967) and auto/biographical work (Bogdan and Taylor, 1976 and 1982). There is a difference between seeking the views of people with learning difficulties and taking them seriously: one of Bogdan and Taylor's criticisms of Edgerton's work is that he did not place as much validity on the views of his respondents with learning difficulties as on case notes and other sources.

Research in the 1970s and especially 1980s became heavily influenced by normalisation (Chappell, 1992) and research with this value-base has tended to have an emphasis on services (e.g. Ward, 1986; Humphreys et al, 1987). Until the 1980s, it was rare to seek the views of people with learning difficulties themselves (Richards, 1985) and then attention was paid to establishing their reliability as respondents (e.g. Sigelman et al, 1981). Much work into, for example, quality of life, has sought the opinions of people with learning difficulties using standardised measures (e.g. Felce and Perry, 1993). A focus of learning difficulty research in the 1980s and 1990s has been the experiences of people leaving institutions and moving into the community, and this research has developed qualitative work based on the views of people with learning difficulties (e.g. Flynn, 1987; Booth et al, 1990).

Though much learning difficulty research remains quantitative (see, for example, British Institute of Learning Difficulties, 1996), trends in the 1990s have been towards relationship-based and in-depth work (e.g. Booth and Booth, 1994), and biographical methods (Atkinson, 1993; Walmsley, 1995; Goodley, 1996). New developments now are towards participatory research, as debates in disability research (Oliver, 1992; Zarb, 1992) and user involvement (Barnes and
Wistow, 1992; Bercsford and Croft, 1993) are applied to learning difficulty research, both in discourse (e.g. Barton, 1996) and practice (e.g. Richardson, 1997; Stalker, 1998). My work is thus an example of the development of participatory research with people with learning difficulties.

2. The 'hegemony of disability'

Chapter 2 discussed my dialectical materialist framework, based on the social model of disability, which has significant implications for methodology. Oliver (1996) has provided a useful framework for explaining the process. His explanation of the 'hegemony of disability' - the combination of ontology, epistemology and experience - shows that the way disability is understood informs the strategies developed in response to it and from that the appropriate research methodologies (1996, pp.29-38).

He argues that if disability is understood as personal tragedy, that influences the strategies developed to respond to it. Theorising is in terms of prevention, cure, adjustment, deviance, stigma etc. Research methodology tends to be positivist or interpretative (note that he considers that an interpretative methodology can still fall within this paradigm). Thus the traditionally dominant individual or medical model of disability has been the starting point for strategies dealing with disability, the type of research conducted and the methodologies that flow from that. Rioux (1994) has described much of this research as similar to research into measles in its medical approach. Oliver argues that alternative ways of understanding disability lead to different strategies and different research methodologies.
This is the basic starting point for examining the methodology appropriate to my research. As the discussion in this chapter develops, however, I will show that precisely which methodology is best suited to the social model is contested. In a seminal paper, Oliver (1992) argued that the social relations of research production should be overturned. He called for emancipatory research, based on reciprocity, gain and empowerment, with researchers' skills and knowledge 'put at the disposal of their research subjects, for them to use in whatever ways they choose' (1992, p. 111). In the same volume, Zarb (1992) argued that social relations are based on material relations. Until material relations change, he argued that emancipatory research is not truly possible, and participatory research is the best we can hope for. This would mean that emancipatory research is that which is wholly owned and controlled by disabled people for their own ends; participatory research is work in partnership, but within the restraints of current material relations.

The issue is still not clear, however, since elsewhere the two terms are used interchangeably (e.g. French, 1994, Sample, 1996, stresses similarities), while other disabled academics, though upholding the (revised) social model, have reservations about emancipatory research (such as Shakespeare, 1996b). Variations on the theme include co-operative inquiry (Heron, 1981), partnership research (Lloyd et al, 1996) and participatory action research (Sample, 1996). Swain (1995) identified six approaches: research as praxis, critical research, democratic research, emancipatory research, co-research and participatory research.

To reach some clarity about the methodology appropriate for this project, it is therefore important to go back to the arguments in social research which have helped to inform current debates, and particularly to see how these have played out in learning difficulty research.
3. Quantitative research and lost voices

This section discusses quantitative research and issues of objectivity and partiality. Early 20th century research on people with learning difficulties was largely of a medical nature. People were objectified as medical phenomena; generalisations were made which could label and characterise people and justify treatment (see Ryan and Thomas, 1980; Digby, 1996; Jackson, 1996).

French (1994) argues that if researchers choose a stance based on a medical model they and their research may become a further source of oppression. One example of this is Miller and Gwynne's 1972 *A Life Apart*, an investigation of institutions for disabled people. They showed what Morris (1991) describes as a classic pattern of prejudice: they were stressed by what they experienced, doubted what they were told, and instead concentrated on the psychological state of the disabled people. Paul Hunt, an 'inmate' in one of the institutions Miller and Gwynne researched, was outraged by their work and wrote about his response (cited in Morris, 1991). On the positive side, research into institutions (like that of Miller and Gwynne, and Pauline Morris, 1969) played a significant part in exposing the injustice of institutions and helped lead to policy and practice change. But still only one side of the story was told: only the 'experts' had spoken (Atkinson, 1997).

Until the 1980s people with learning difficulties had not generally been considered capable of being respondents in research.

'For persons with profound disability and communication problems in particular, there has been an almost systematic and institutionalised exclusion of their views.'  
(Ramcharan and Grant, 1994, p.233)
In 1984, a survey of learning difficulty research could only find five studies that had actually sought their views (Richards, 1985). This is similar to the points made by feminists regarding the exclusion of women's views:

'While studying women is not new, studying them from the perspective of their own experiences so that people can understand themselves and the world can claim virtually no history at all.' (Harding, 1987, p.8)

Bryan et al (1985), writing the story of black women in Britain, comment, 'so much of our story lies buried' (p.2). This is even more true of people with learning difficulties.

There were notable exceptions to this trend. Edgerton's ethnographic study in the 1960s (1967) and Bogdan and Taylor's autobiographies (1982) both sought the views of people with learning difficulties using qualitative methods. These are discussed below. The dominant trend, however, remained quantitative work and there is still a preponderance of such studies, even of subjects such as empowerment (Zirpoli et al, 1993) and expression of feelings (Lindsay et al, 1994). A glance at any issue of the British Institute of Learning Disability (BILD) Current Awareness Service illustrates this (for example, BILD, 1996).

Using observations and measures such as before and-after studies, measures of 'engagement', counting the number of visitors, etc., all have their value, but miss out the ingredient of the people themselves. Filling in a questionnaire in itself excludes most people with learning difficulties. Most quantitative studies rely on other people (staff, parents) to fill in the forms. In quantitative research subjective insights disappear in statistical data. Simply filling in a questionnaire lets the researcher know little of the experience of the person: it is, at best, a snapshot rather than a moving picture. And quantitative measures may not even provide that snapshot: Sidell (1993), in describing her experience of methodological pluralism, shows that her
quantitative data produced a straight line which, while of value in itself, did not actually represent the real experiences of any one person, which were shown by qualitative material to be fluid and to fall on either side of the line at different times.

Positivist approaches using quantitative methods are justified by claims to scientific objectivity. However, researchers do not operate in a vacuum. We are influenced by a host of factors from the most concrete to the most general. We do research for reasons: even if we want to change the world, we also might want a qualification or to get or keep a job. Our research may be funded for a particular purpose. More generally, we are a product of a particular stage in history and research methods develop out of prevailing ideologies.

'The class which has the means of material production at its disposal, has control at the same time over the means of mental production...' (Marx, 1963, p.93)

Researchers who do not consciously take on an alternative position will by default be perpetuating the dominating perspective. Feminists argue this too - Oakley (1981), for example, argues that traditional methods develop out of the dominant group's influence over culture and overall outlook (which she characterises as masculine). This means that we cannot be objective, and attempting to be so could have serious consequences. So-called objectivity may actually deny reality and may create a distance between researcher and researched that is insensitive and intrusive. Arguing for objectivity is really the 'inequalities of power and the dominance of the researcher's values and judgements' (Beresford and Croft, 1986, p.21).

Mies (1983) argues for conscious partiality, that is, open support for particular values or interests. This I believe to be correct, but again it is not without its possible pitfalls: the important point is *which* values. In some ways, not seeking the views of people with learning difficulties has been perpetuated by research which has used normalisation as its explicit value-base. Chapter 2
discussed the dominance of normalisation in learning difficulty services. Chappell (1997) outlines the history of normalisation, from an idea that was heaped with scorn and derision and therefore had to be strong in defence, to becoming the accepted wisdom which it was heresy to criticise. Walmsley describes it as 'incontrovertible dogma' (1997, p.64). A powerful model, offering a 'dream' of high quality services, it has been a driving force of much research. Normalisation-based research (such as that into the New Ideas for Mentally Retarded in Ordinary Dwellings (NIMROD) service, e.g. Humphries et al, 1987) is based on a conscious partiality. This has not meant that researchers felt the need to consult people with learning difficulties adherence by the researcher to normalisation is seen as sufficient (Chapell, 1992). Power relations are not questioned, the research assumes disability, 'norms' and values as given. Much of this research itself is quantitative, measuring visits, levels of support etc.

Empathetic research is also explicit in its partiality - what does it feel like to be disabled? but produces data that is interpreted from a non-disabled point of view, and could use any model of disability as its framework for understanding. One example is Williams (1978), who expresses the views he believes would be held by someone with learning difficulties, and uses this device to propagandise the principle of normalisation. Conscious partiality on its own is not enough - we have to go further and keep as the aim the perspective of the person with learning difficulties.

A primary concern of some studies has been to test the reliability of people with learning difficulties as research respondents. Influential work by Sigelman and others tested people using different kinds of questions to determine their ability to be respondents, and this still goes on today (e.g. Sigelman et al, 1981; Heal and Sigelman, 1995). They found low levels of responsiveness to open-ended questions; high levels of acquiescence (i.e. saying yes to appease
the questioner) and recency (i.e. choosing the last from a choice of possible answers) with closed question-types; and low correlation between the answers given by people with learning difficulties and others. Problems with variants of question formats, acquiescence and recency are thus well-documented and most studies take these difficulties into account (e.g. Atkinson, 1988; Booth and Booth, 1994).

However, while not overlooking the real difficulties posed in interviewing, Simons et al (1989) point out some failings in Sigelman's studies. Questions like 'Are you usually happy?' are in themselves ambiguous, and in any case people's state of happiness will change at different times eliciting different responses. Asking the same question several times over or asking obvious questions like 'Is it raining?', will probably lead to confusion, causing people to think there is a catch or that their first answer was wrong and they should say something else. The apparent basis of Sigelman's work is that acquiescence or inconsistency is a function of impairment. Simons et al (1989) instead suggest that they are more likely to be the impact of experience, the reflection of ambiguous or changing feelings and the result of confusing and pressured interviewing methods. This does not mean that we overlook such risks, but that we work to overcome them rather than see them as automatic. There is also an element here of people with learning difficulties being expected to reach a higher standard than the rest of us: we are all inconsistent - our moods vary, the context of the interview varies, our responses depend on a host of factors of which the researcher will not necessarily be aware. This analysis points to the need for a different type of approach.

This section has discussed the dominant methodology in learning difficulty research this century and raised issues of objectivity and partiality. I have suggested that traditional methodology,
based on an individual model of disability, has tended to objectify people with learning difficulties and ignore their views. I have argued against the possibility of objectivity in social research, but that conscious partiality in itself can override the views of people with learning difficulties. In the replacement of claims to 'value-free' research, it is the particular values that are important. I have argued for the voice of people with learning difficulties in research, and pointed out that while awareness of risks of acquiescence etc. is important, it is again methods based on an individual model of disability which assume these risks as functions of impairment, rather than looking for alternatives which will help to overcome them.

In the 1970s and 80s, feminists challenged the foundations of quantitative work based on positivist methodologies. They argued that far from being an impartial, purely scientific approach leading to the creation of general truths, methods based on a positivist methodology were hiding power-relations (which they define as gender-based) behind this veil of science, leading to the generation of 'facts' based on the dominant groups' assumptions and interests. The next section addresses in particular the question of power and the development of qualitative methodologies.

4. Power and qualitative research

Power relations are a vital theme in most research which challenges traditional methods, whether this is described as disempowerment (Beresford, 1992), appropriation (Opie, 1992), commodification (Ramcharan and Grant, 1994), alienation (Rowan, 1981), or as embedded in the social relations of research production (Oliver, 1992; Zarb, 1992). Davis (1992) asked people who had been researched about their experiences. She found that being researched felt like intrusion or like being used; there was a fear that what respondents said might be used
against them, or that if they did not co-operate they might lose out. It was felt research was used to invalidate user experiences. Similar points are made by feminists such as Oakley (1981), Roberts (1981) and Finch (1984b). Barnes' (1994) experience tells her that some people with learning difficulties have found the research interview to be as disempowering as their interactions with some professional care providers. She believes research has a moral onus not to add to feelings of disempowerment, and if possible to contribute to its alleviation, and she believes that this should mean sharing some control over the research.

It can be argued that researchers are not really all that powerful (e.g. Hammersley, 1995). For example, we have to negotiate access. In my own work I experienced the difficulty of reaching people with learning difficulties directly because of the staff and families who protect access. Bell's (1978) argument about the locally powerful, giving or withdrawing permission, controlling access, etc., is relevant here. The theory of street level bureaucracy (Hudson, 1989), about the power of ordinary front-line service workers, is similarly useful for understanding the ability of workers to refuse access to researchers.

It is true that power is not a straightforward one-sided issue. Atkinson (1997), for example, discusses her feelings of lack of power in group oral history work, as group members followed their own agendas. Bornat explains how her view of her own power has changed:

'Though I still see the interview as a power relationship, I think I can see different expressions of power and purpose on both sides. I think I am now more prepared for the grit and determination which the other person is mediating and less inclined to think only in terms of disempowered victims. Though I am no less wary of creating an exploitative relationship, by "mining" someone's past, I now see evidence of conscious collusion with the outcome in some cases, and positive enjoyment in participation in others.' (1993, p.94)
Barnes (1994) found that some people with learning difficulties have enjoyed the attention and interest shown in them, and some have received material benefits from research. But she also found many who felt tricked, and only participated because they feared they would lose out if they did not.

Research is usually a small and marginal part of someone's life; it does not form part of the permanent power structures. But this must not cloud what power we do have. As researchers we ourselves can have the power of the 'street-level bureaucrats'. We must also consider who controls the research, in whose interests. Zarb explains that

"...we operate within a social structure which seeks to silence all oppressed groups, and neutralise any criticism or protest..." (1992, p.132)

Research with people with learning difficulties is research with people who may have been subject to all sorts of blatant and subtle abuses of power throughout their lives. If carried out in a hierarchical, disempowering fashion, research can compound that experience. When they agree to be studied (assuming they are asked) it is likely that many people with learning difficulties will have little real understanding of what the research is about, what is expected of them, and what will happen to what they say, especially if it is poorly explained. It may well be that someone discloses very little, but this does not necessarily mean it is because they have power. It may be a lack of power, a fear of the consequences of talking. It is therefore important to consider ways of reducing power imbalances, or of reducing their effects.

Edgerton's early 1960s ethnographic study sought the voice of people with learning difficulties for the first time. Edgerton's work has been criticised for not taking people's views seriously, seeing case notes as facts and people's own accounts as 'fabrications or rationalisations' (Bogdan
and Taylor, 1982, p.211), though Edgerton has defended himself against this (1993). His work was ground-breaking, leading to the acceptance that the views of people with learning difficulties are worth seeking, and that seeking their views takes time. There are few similar ethnographic studies. One example is Wilkinson (1989), who got to know people by 'being there'.

Since the mid-1980s there has been a growing number of studies seeking the views of people with learning difficulties. Possible problems with acquiescence etc. of course must not be dismissed, but can be best overcome with a more informal, relationship-based approach. Some studies have used fairly structured interviewing, for example Malin (1983), Passfield (1983) and Flynn (1987). Malin and Flynn both concluded that less formal, less structured interviewing would be preferable to allow people to talk more freely. Simons et al (1989) advocated taking time to get to know people and their ways of communicating, using an unstructured, informal approach. Their study of the Kirklees Relocation Project with this approach had no problems with acquiescence or recency.

It is now accepted by a number of researchers that better quality data results from the quality of the interviewing relationship. In interviewing women in the transition to motherhood, Oakley (1981) found that they kept asking questions back, and she established a personal involvement it was unhelpful to avoid. In interviewing over time a relationship develops, leading to a collaborative approach and a greater quality of information. Remaining detached and 'objective' does not help rapport. People would not give so much if you did not give them something back:

'...personal involvement is more than dangerous bias - it is the condition under which people come to know each other and to admit others into their lives.'

(Oakley, 1981, p.58)
Some researchers into learning difficulty have developed *getting to know you* styles, for example, Brandon and Ridley (1983), Sugg (1987), Atkinson (1988) and Connelly (1990). Particularly notable is the recent work of Booth and Booth, using in-depth interviewing on a long-term relationship basis to come to an understanding of the experiences of parents with learning difficulties (1994). They see this as a way of gaining new insights, knowledge and perspectives, and of improving accountability. I adopted this approach to gain a fuller understanding of subjective experience.

Use of biographical methods is a development with great potential for discovering the lived experience. There is much from oral history that has been of use in my pursuit of finding out some of the experience of self-advocacy and families. Oral history traditions explore the experience of people excluded from traditional history, producing versions of history which tend to go unnoticed by historians (Bornat, 1993). There are many examples, such as the Hall Carpenter Archives' 1989 collection of lesbian life stories, *Jewish Women in London* (1989) and Keith's 1994 anthology of writings by disabled women.

There has been a growth of oral history in last 30 years (Bornat, 1989). Atkinson (1997) points out that this movement has largely left out people with learning difficulties. A possible reason for the rarity of this material could be the apparent paradox that those who most need to have their stories told may be least able to tell them: people with learning difficulties have generally lacked the opportunity and tools for such an exercise and will very often be restricted in their ability to do so unaided. Atkinson (1997) advocates auto/biographical methods, with both the voice of the person and the researcher, and setting the individual against her or his social background.
The recent development of biographical methods with people with learning difficulties is part of
the growing interest among researchers to use anti-oppressive, empowering measures, and part
of the recognition that 'researchers should attend more to their own deficiencies' (Booth and
Booth, 1996, p.17). Telling the story from the point of view of people with learning difficulties
has been an important dimension to the self-advocacy movement, as seen in chapter 2. Bogdan
and Taylor explain their 1970s presentation of Ed's story, the life of a person living in an
institution, as coming from a 'different kind of relationship with a person we might otherwise
casually dismiss as dumb or incoherent or "not all there"' (1982, p.17). Fido and Potts (1989)
recorded the memories and experiences of residents and ex-residents of a mental handicap
institution. The Open University has produced an anthology of writing and pictures by people
with learning difficulties (Atkinson and Williams, 1990) and carried out group-based
reminiscence and oral history (Atkinson, 1993 and 1994). There has also been an interest in
applying biographical methods to other forms of research. Booth and Booth (1994) used
narrative methods to research the experience of parents with learning difficulties, and Walmsley
used biographical methods to research caring (1995). Currently, similar methods are being used
to examine the experience of self-advocacy groups (Goodley, 1996).

The application of these methods is not without difficulties. Booth and Booth (1996) looked at
the challenges in using narrative methods with inarticulate people, devising various methods to
create a flowing story. Booth (1996) argues for techniques more associated with fictional forms,
such as attention to character, pace and structure of the story, and the construction of dialogue
from original fragmented words. There are dangers here in distortion of meaning, but Booth
points out that life history work with people with learning difficulties is inevitably a collaboration
due to intellectual limitations. Goodley (1996) warns of dangers in ignoring the social order in
pursuit of individual subjectivity; particularly that failure to locate the person in social theory may jeopardise a person's words, leaving them open to being cast in the medical model.

From a materialist perspective, I endorse the importance of placing people in their social context. Materialism views social life and history as being 'rooted in the material conditions of life' (Marx, 1963, p.67). In understanding individuals, we must be able to relate individual experiences to the historical and social context in which they exist. 'Life is not determined by consciousness, but consciousness by life' (ibid., p.90). A dialectical approach, in addition, means we cannot just look at the surface picture but must look at the processes underneath. Auto/biographical approaches have a keen awareness of context, material inequalities and social and political environment, understanding the multi-layered nature of lives.

This section has discussed the development of qualitative approaches in the context of attempts to use anti-oppressive methods that tackle power relations. The next section takes this approach further:

5. Participatory research

This section looks at participatory research among people with learning difficulties and addresses the ongoing and complex debates within disability research. Oliver (1992) argues that rejecting the positivist approach, and turning towards relationship-based and biographical methods, does not necessarily overcome problems of power: qualitative research can be just as alienating and disempowering because it does not fundamentally change the social relations of production.
'The social relations are built upon a firm distinction between the researcher and the researched; upon the belief that it is the researchers who have specialist knowledge and skills, and that it is they who should decide what topics should be researched and be in control of the whole process of research production.'

(Oliver, 1992, p.102)

This research relationship has been analysed using Marx's forms of alienation (Rowan, 1981). The relationship is alienating because it is using the person for someone else's ends - the person's actions do not belong to that individual, but to the researcher and to the research plan. Addressing the balance of power is therefore only possible through the overturning of the research relationship. Participatory research means involvement through the research process of people who traditionally have been seen purely as research subjects (or even 'objects'). It requires that assumptions about who is the researcher are turned upside down.

Feminists similarly have advocated women researching women as a way of challenging power relations (e.g. Stanley and Wise, 1993). Finch (1984b) argues that a shared powerlessness between interviewee and researcher is important. Application of this to disability research should logically mean disabled people researching disabled people. However, we have to be cautious about whether notions of shared powerlessness are possible. It is illusory to imagine that because two people are of the same particular identity that their power is the same. The feminist idea of shared powerlessness has been somewhat discredited by disabled feminists. As discussed in chapter 3, Keith (1990) and Morris (1991) criticise feminism for creating a dichotomy between carers and cared for, portraying disabled people as 'passive, feeble and demanding' (Keith, p. v). Morris points out that feminists who investigate community care never ask disabled people about their views, and argues that disabled feminists would ask different questions (Morris, 1991). In my view, although this is an attack on the earlier feminist ignorance of disability, it does not
undermine the basic notion of ways of tackling power issues: Keith and Morris both advocate
disabled people having more control over research.

Oliver argues not for participatory but *emancipatory* research (1992 and 1996). Emancipatory
research is that which is wholly controlled by disabled people and aimed at emancipatory change,
although it may still use the knowledge and skills of non-disabled researchers. It is therefore
about both process and outcome, and is crucially about the relations of research production (who
commissions research, who owns it, for whose purposes is research conducted etc.?).
Participatory research is that which is conducted within traditional research relations, with
researchers inviting people who would otherwise be seen only as respondents to participate in
the research process. It is a recognition of current material relations (where the money lies, for
example) that leads Zarb (1992) to propose participatory research as the best most researchers
can manage, which Oliver (1996) accepts as long as emancipatory research is still the aim.

North (1995), researching refugees, says that there are obvious reasons why refugees are not
likely to carry out research. This could be applied to people with learning difficulties. In addition
to their impairment, their social position makes carrying out research alone unlikely, with no
access to research and/or any expectation of ever doing such a thing. Those bits of participatory
research which do take place are oases in what still amounts to a desert of opportunity.
Involvement in participatory research could therefore be empowering and be a transition to more
control. But it does not *have* to be a transition - participatory research does have value in its own
right. For many people full involvement in a research project may be liberating; for others it may
be daunting; for others it may just be plain tedious. It may not even be possible, given current
power relations in both research and wider society, to erase all unequal or potentially exploitative
elements of the research process. A note of caution, however: power in learning difficulty
research is with non-disabled academics and we dominate the debate. We must take care that
these points do not defend conservatism, and excuse low levels of participation when more could
be possible.

Not all disabled researchers support the goal of emancipatory research. Shakespeare, a disabled
academic associated with the disability movement, carries out qualitative but not emancipatory
research. He is sceptical about the ability of research to make change and says that research with
an 'axe to grind' could be dismissed out of hand (by governments etc.) (1996b). This raises
questions of the purpose and authority of research. In terms of its purpose, Hammersley (1995)
argues that research should not be directed toward anything other than the accumulation of
knowledge. However, it is difficult to see how this is possible, if we take an understanding of
knowledge as socially constructed rather than just waiting to be found. We cannot talk of pursuit
of knowledge as if it stands above society. The very fact that we are investigating anything is
because someone wants to know.

Shakespeare does not go as far, but does comment that it is action that decides the day. This is a
useful warning against excessive claims for research, but in my view a little one-sided. There are
many examples of research having an effect. Action research is meant to bring about change:
evaluative research such as normalisation's PASSING tool (Wolfensberger and Thomas, 1994)
has a view to improving services. Research into long stay hospitals had an impact (Morris,
1969). Research can effect change, and therefore it is important to raise questions about change
in whose interests.
There is evidence to suggest that many disabled people do not feel that much research is conducted in their interests. French (1994) says that disabled people may feel money is wasted on research which does nothing for them. Barnes (1992b) found that research is often thought of by respondents as a substitute for action. Davis (1992) found little evidence of a demand for research from people who had been respondents, and that research had not played a positive part in service change. Oliver (1993) believes that because much disability research has contributed little to improving quality of life, more disabled people are refusing to take part. Research should benefit people in ways they find useful.

Shakespeare (1996b) also makes the point that research with a vested interest will not be taken seriously, and distinguishes between commitment to disability politics (which he espouses) and accountability to a particular organisation. On this specific point, I would argue that any research institution has vested interests. If 'official' bodies want to ignore or discredit research, commitment to disability politics could be used to invalidate it as much as accountability to any particular organisation. However, there is a broader point about the authority of research. Hammersley (1995) argues that research involves a claim to intellectual authority, which brings with it an obligation to ensure that information is valid and that the research is carried out rigorously and properly. This is an important point, and I would not be in favour of undermining scientific rigour, but this does not dictate who can be a researcher. We have to ask the question, authority in whose eyes? This seems to me to go back to the question of power relations, and the relations of research production. Opening up these relations would broaden the conception of who uses research results and judges its authority.
Hammersley's point also raises the important question of intellectual ability, which is particularly pertinent to people with learning difficulties. I shall return to this point, after first looking at the development of participatory research among people with learning difficulties.

Despite the developing debate, there are still few opportunities for disabled people to participate in disability research (Oliver and Barnes, 1997). There are some examples of participatory research with, for example, older people (Lewisham Older Women's Health Survey Project, 1994). When I began this project in 1994 there were hardly any examples with people with learning difficulties. Cocks and Cockram (1995) suggest that this is due to two types of reasons: one, limitations or unwillingness on the part of academics, and two, because it is difficult to do with people with an intellectual impairment. These two elements, social and environmental manipulation (as removal of barriers is termed by French, 1993a) and the reality of impairment, are returned to throughout the consideration of research approaches.

Developments in user involvement have been an influence on the participation of people with learning difficulties in research. User evaluations are a recent and expanding development. The evaluation carried out by People First London in 1990 of residential services in Hillingdon (Whittaker et al, 1991) was a landmark. With community care reforms and the growing voice from self-advocacy groups, there has been a proliferation of user-led evaluations of services, though unfortunately most are not published. Practitioners and writers in user involvement are strong advocates of participatory research, applying the same demands to research that they make of services (Beresford, 1992). Barnes states that, 'Researchers should be just as aware of the values that inform their work as are those concerned with service provision' (1994, p.1).
This development is only slowly being matched in the academic world, though in the time since I began my research, the number of such projects has increased. A team at the Norah Fry Research Centre describe research which involved people with learning difficulties (Minkes et al., 1995). In one example, a group of people from a day centre carried out a postal survey of service users, and presented the results, supported by their group worker and a researcher (Townsley, 1995). Sample (1996) describes a project combining participatory with action research. Ward gives several examples of people with learning difficulties being involved at different levels, from being interviewed, advising, 'involvement at every stage', to people carrying out their own projects (1996). A team at the University of Stirling is investigating the conditions required for a learning society (Stalker, 1998), and Richardson (1997) at the University of Leeds, is researching people with learning difficulties' experiences of nursing. These are both participatory projects.

A project looking at crime against people with learning difficulties used parallel text to make the research report accessible (Williams and Bashford, 1993; Bashford et al., 1995). There are a few examples of separate reports written for people with learning difficulties, using pictures and simplified, larger text (e.g. Simons, 1993a), and parallel texts including illustrations have been used elsewhere (e.g. Mitchell, 1992). There is also the Plain Facts project, which makes relevant research projects accessible to people with learning difficulties (Townsley and Gyde, 1997).

Barton poses the question: are these developments with people with learning difficulties 'transformative vision or discourse of delusion?' (1996). This question remains unanswered in the literature, and, in attempting to find an answer, my work makes an important contribution. Researchers argue for participatory research and give glowing examples - what is needed now is
the real story! Stalker (1998) gives an honest discussion of her work and raises the question of the reality of intellectual impairment. The social model of disability could be interpreted to imply that all that is wanting is to overcome society's barriers, but, as French (1993a) points out, the reality is that people do have impairments. The reality of impairment and personal experience is starting to be discussed within disability theory, e.g. Crow (1996), Keith (1996) (see chapter 2).

If we are to take participation of people with learning difficulties seriously, then we must acknowledge the impairment and the implications this might have for genuine involvement.

Stalker correctly argues that we need to hear more about the views and experiences of the people with learning difficulties involved in these processes. A first in this area is the article published by the co-researchers on this project (March et al, 1997 - see chapter 5).

Walmsley (1997), in discussing the involvement of people with learning difficulties in an Open University course team, also raises important questions about the ability of people with learning difficulties to carry out academic work. She makes a number of observations. The contribution of people with learning difficulties is nearly always personal and others comment on and interpret their lives. People with learning difficulties always seem to need prompting and advice in their involvement. Co-authoring raises problems regarding accessibility of material, which audience to aim at, who controls the analysis and obtaining sufficient resources. After involvement in research people with learning difficulties tend to go back to their previous lives rather than use their new skills elsewhere. Walmsley asks if these points are to do with social barriers or because of the impairment. These issues will be returned to in the light of my experience in the next chapter. My tentative view at this stage is that this is a live and changing debate and the boundaries are expanding. While people with learning difficulties undoubtedly have intellectual limitations, the risk in attempting to draw a line, rather than constantly pushing forward what is
possible, is that we fall prey to the dangers of the individual model of disability and positivist methods.

The way that these ideas fit with the principles of academic research should be discussed, and will be returned to in chapter 5 in the light of my experience. It seems that most research projects actually carried out by people with learning difficulties themselves, in which they hold real control, are those carried out outside the academic arena (e.g. People First London, 1994a; Townsley, 1995). The King's Fund has compiled a book of examples of people carrying out evaluations and research (Whittaker, 1997). One example of people carrying out their own research within an academic context may be the plans to research self-advocacy in Europe (Williams, 1996).

Real involvement makes substantial resource demands. Until relations of production change, in itself dependent on bigger changes, there will not be enough resources to do everything. But despite the difficulties still evident, there are now changes taking place. Major funders such as the Joseph Rowntree Foundation now expect some level of participation in those projects to which they make grants (Ward, 1996). This is an immense step forward. Nevertheless, there are significant other factors which make participatory research difficult - established practices in bidding and commissioning, expected standards in writing, the demands of research committees and so forth. I would tend to agree with Stalker (1998) that much of academia is not compatible with emancipatory research, unless academics are themselves to be 'bought in' by projects run by disabled people. Even participatory research makes substantial demands.
This section has examined the debates within participatory research. I have discussed research relations and issues to do with the purpose and authority of research. The purpose of research cannot be separated out from the interests of those who engage in it. I maintain that opening up the process of production does not necessarily undermine the authority of research. To suppose that it does assumes that research relations stay the same (in regard to who judges and gives work legitimacy) and also makes assumptions about the ability of non-academics to do research. The section has raised questions about intellectual impairment, and tentatively advocated caution in assuming what people with learning difficulties can and cannot do. The following chapter develops this more fully in relation to my experience. Much of academia is not compatible with emancipatory research, but, within the constraints of the current time (such as control over finance and other resources), there are steps that researchers and practitioners can take to reduce the exploitative and disempowering aspects of their work and make research more participatory. The next section discusses reflexivity, a crucial aspect in dealing with these issues.

5. Reflexivity

This chapter has challenged some of the claims made about objectivity, and supported being reflective about values. I have argued that rather than being kept hidden, the motivations and values of researchers should be open to examination; and that an in-depth, qualitative process allows for a deeper understanding of respondents' lives. There are dangers in this type of work, for example, in the possible influence exerted on respondents through the development of the research relationship, or through immersion in people's lives leading to 'submersion' (Atkinson, 1997). Throughout this and the next two chapters I refer to reflexivity as a safeguard. Being reflective is part of the qualitative research process.
Reflexivity has been established by a number of feminist and other qualitative researchers as integral to their work (e.g. Reason and Rowan, 1981; Roberts, 1981; Bowles and Duelli Klein, 1983; Goodley, 1996). As Steier (1991) argues, knowledge is culturally and socially constructed, so that the researcher and the researcher's actions are part of the process and should be subject to self-reflection. Atkinson and Shakespeare (1993) discuss reflexivity in relation to three areas: the self, research 'subjects' and practice. In regard to the self, they describe a circular process:

'The self, the "I", is part of writing and research, and interacts with ideas and people. But "I" can also stand back and reflect critically on that process.' (1993, p.4)

This inevitably means self-disclosure in performance and writing, an honest reflection of one's own research practice, and disclosure in interviews as a means of establishing rapport. It means developing a self-awareness - an awareness of the influence of self in a research situation. Harding (1987) argues that placing the researcher's background, interests and values in the frame opens them to rigorous scrutiny, and thereby reduces the risk of distortion.

In regard to the research respondents, 'other-awareness' is a first step for the researcher towards sensitive interviewing and an empathetic approach. Reciprocity, and a commitment to reducing the power differential, are enabled through a reflective approach and awareness not just of self but of the respondent. Similarly, reflection applies to research practice and its effects. Chapter 6 looks at reflexivity in practice.

There are important ethical dilemmas in participatory research which can only be dealt with reflexively. Davis warns of being '...in danger of sounding no different from service providers who promote user participation because it is fashionable to do so' (1992, p.36). Stanton asks, 'Are researchers trying to bring people in to what remains principally the practitioner's concern?"
(1989, p.322). Are we just trying to ease our consciences (Lloyd et al, 1996)? It is important to analyse our motives carefully and not allow ourselves to become complacent.

Bernard (1994) shows that questions of power are not resolved simply by an 'insider' carrying out research. In interviewing a black woman as a black woman, she says,

'It became apparent to me... that it mattered little to her that we shared the same gender and race. Black respondents may view a black researcher as a member of what they perceive to be the white establishment, and even as a threat to their existence... That the researcher is also a black woman does not necessarily mean that concerns about the uses and abuses of research are lessened in the mind of a black respondent. Research could be carried out by a black researcher utilising frameworks which are Eurocentric and reproduce racist discourses about the black community.' (1994, p.21)

Suk Tak Tam, researching the Chinese community, warns against 'ethnic credentialism'.

Although ethnic minority professionals may have language skills and more experience in multi-racial practice, 'they do not necessarily possess a monopoly of the truth' (1994, p.16). This can be applied to disability research:

'Analytically, the experience of impairment is not a unitary one... Having an impairment does not automatically give someone an affinity with disabled people, nor an inclination to do disability research. The cultural gap between researchers and researched has as much to do with social indicators like class, education, employment and general life experiences as with impairment.' (Barnes, 1992b, p.122)

Participatory research does not absolve the researcher from reflexively analysing power relations.

This brief section has shown the safeguards and value of the reflexive element of research. Constant questioning and attention to possible pitfalls keeps questions of power, exploitation etc. to the forefront. In this way what may on the surface seem to be drawbacks or dilemmas become part of the process; an exploration of these becomes one of the strengths of the enterprise.
6. Conclusion

This chapter has examined issues in quantitative, qualitative and participatory research. I have justified my qualitative and participatory approaches. Participatory research is not a static phenomenon, it is a developing idea, without fixed rules and boundaries. I have shown that the debates in disability research are complex and no one model of participatory research emerges. I conclude this chapter by setting up the model of participatory research I used in my research.

Participatory research endeavours to involve people traditionally seen purely as research subjects in all aspects of research production. No element in the following list (from a range of literature) is more important than the others. The suggestion is that researchers attempt to make all aspects accessible. We should ask who…?

- commissions and funds
- defines the topic
- explores the issues and the literature
- develops criteria and questions
- chooses methods and designs the research
- carries out the fieldwork
- analyses and interprets
- writes and disseminates the results
- owns the research
- gets something out of it

(Cocks and Cockram, 1995; Davis and Fleming, 1992; Oliver, 1993; Ramcharan and Grant, 1994; Rowan, 1981; Stanton, 1989; Zarb, 1992).
When I began my research in 1994, there were even fewer examples than now of participatory research with people with learning difficulties. The question of how to involve people was undeveloped and so the process has been experimental and evolving. My work can therefore be seen as a significant contribution to participatory research. A reading of the literature suggested two possible models, shown in figure 1. Model 'A' is where people with learning difficulties, respondents of a research project, are brought into the process of production of that same project. This is the model used by Sample (1996). Model 'B' is where people with learning difficulties become co-researchers, who then carry out a research project with others as respondents. This is the model described by, for example, Townsley (1995).

I chose model 'B' as a more straightforward beginning. The first model suggests to me the need to find quite a large group wanting to carry out a research project - much harder to find among people who will in the main be unfamiliar with research. Chapter 5 will explain how my chosen model changed in practice and address the issues that arose from this change.

I have used the term 'co-researchers', as used by Reason and Rowan (1981), to describe the people with learning difficulties who participated in the research process with me, to distinguish them from the respondents.
Model 'A'

researchers

respondents and co-researchers

Model 'B'

non-disabled researcher(s)

co-researchers
with learning difficulties

respondents

Figure 1: Participatory research models
This chapter has discussed the theoretical basis of both participatory and qualitative research.

There now follow two practice chapters: 5 on my practice of participatory research, and 6 on qualitative methods.
Chapter 5
CO-RESEARCHING IN PRACTICE

1. Introduction

The purpose of this chapter is to describe and analyse the experience of participatory research on this project. I have worked with three people with learning difficulties as my co-researchers for more than four years. Chapter 4 set out a model for participatory research, and indicated that the practice with people with learning difficulties is only beginning to be discussed. Jan Walmsley (1997) and Kirsten Stalker (1998) have raised significant points in this regard, which I address in this chapter. I set my experience against the model from the previous chapter, which acquired fluidity rather than remaining fixed throughout. There is a natural narrative in the experience which is reflected in the chronological structure of the chapter.

I begin by addressing the question of finding co-researchers and deal with issues of criteria, access, consent and negotiation. I then discuss the overarching issue of the relationship between the co-researchers, myself and the research: how I approached the task of ensuring that people's involvement was not token but that we worked together as co-researchers. In this respect, my work makes a contribution both to our understanding and to the development in practice of participatory research.
I then set my experience against the main elements of the scheme for participatory research set out on page 120: involvement in theory (including literature and background issues); planning and design (including setting criteria, choosing methods and setting 'rules'); fieldwork; analysis; and writing and presentation. Participatory research with people with learning difficulties is considered difficult, and this project has extended participation to two areas - theory and analysis - previously considered particularly challenging. This chapter will also show how my work has developed others' experience in terms of writing and presentation of results. The areas where there was less participation (commissioning and choosing the topic; ownership of the research) are discussed at the end of the chapter.

The discussion in this chapter is reflexive: at each stage I consider questions and points of theory from the previous chapter. Issues are highlighted which illuminate the points raised by Walmsley and Stalker, particularly in relation to the reality of impairment and the compatibility of academia and participatory research. The chapter has two conclusions endorsing the discussion in the previous chapter. Firstly, while the reality of impairment must not be underestimated if participation is to be real, the boundaries of what is possible are always moving. Secondly, currently, without wider material changes, academia remains largely incompatible with emancipatory research; nevertheless there is much that academics can do to make their work more participatory.

The process of finding co-researchers is discussed in the next section, but a brief introduction here will help readers through the chapter. All three co-researchers are working-class women from Hackney, London, and members of Hackney People First. The thesis uses their real names, as they have requested, in order to recognise their contribution.
Justine March - 21 years old at the start of the research, black, lives with her mother and brother.

Betty Steingold - 61 years old and Jewish, Betty lived with her mother at the start of the research, but then moved into her own flat.

Susan Justice - 35 years old, white, and from a large family, Susan had moved into her own flat two years before the research started.

2. Finding co-researchers

This section discusses the process of finding co-researchers, focusing on criteria, access, consent and negotiation.

Criteria

I aimed for two to four people so that a good working relationship could develop. I wanted people who lived with their families or had recently moved out, with experience in self-advocacy. The point was to find experts on the issues of families and self-advocacy. I considered it was also important to find people who were fairly capable, in terms of taking part in research, though I could only go on early impressions in this regard. Stalker (1998) stresses the importance of recognising intellectual impairment if we are to take participation seriously. The arguments around recognising impairment within the social model of disability were presented in chapters 2 and 4. For me, this meant taking every possible step to make the research accessible, but it also meant a recognition that co-researching would probably be quite difficult. There would be opportunities for the co-researchers to learn over a long period.
of time, but as a Ph.D student I had to recognise my time constraints and also the fact that I was new to research myself with much to learn. It was particularly important not to allow the process to be tokenistic. The issue of the reality of impairment will be returned to during this chapter.

Access

I approached the local Hackney People First. I was invited to a group meeting as the main speaker, but the adviser to the group (with learning difficulties himself) asked if I would also go to an earlier meeting in place of their supporter, who was off sick. I agreed. One of the aspects of traditional research I wanted to avoid was assuming a detached stance, in the interests of objectivity, yet expecting high levels of disclosure from respondents, or in this case co-researchers (Oakley, 1981). Though I was conscious of the need not to send mixed messages about who I was, I saw helping the group as an opportunity to meet people and demonstrate that I was on their side and prepared to give something back. I could not ask people to commit themselves to partnership in a research project on any other basis. Stalker (1998) correctly points out the difficulties this could pose for my role if offered on a regular basis, but this was a one-off while their supporter was sick.

Two weeks later I was the main speaker. I drew up notes with pictures to help explain what I was doing and what being a co-researcher would mean (appendix 1). Having been there before helped generate interest. The topic of families provoked discussion, and a few people indicated that they might be interested in getting involved. It was agreed that they would go away and think about it, and I would come back again. I wanted people to feel in control, not pressurred, and to have the opportunity to look over the picture-notes and discuss with others. At the third meeting I attended, four people came forward as possible co-researchers.
Consent and negotiation

Brown and Thompson (1997), in a thorough discussion of consent, address the question of power relations and intellectual ability. They consider that the power relations in which people with learning difficulties tend to exist, and their likely susceptibility to influence, mean that the concept of free consent is dubious. Analysing different determining conditions for informed consent, they conclude that whether or not someone can consent should be decided on an individual basis on the premise of as much information as possible. Brown and Thompson recommend the safeguard of an ethics committee. I was not in circumstances where such committees exist so I relied on a scrupulous process.

Seeking consent became an exercise of negotiation. I considered that simply getting people to sign a consent form was unsatisfactory because it would probably mean very little to the person who signed. Such a process could in fact be a way of legitimising a lack of understanding. I wanted to make sure my potential co-researchers (and later, respondents) understood as much as possible what they were consenting to, and to work out with them what being co-researchers would mean in practice. I arranged to meet each of the potential co-researchers individually; one also asked me to meet her mother, and another to talk to his staff. Negotiation included how much time people would be prepared to spend on the research - we agreed monthly meetings, with the clear option of stopping at any time.

I was struck by the altruistic motives of at least two of the co-researchers, who wanted to do the research so they could help others. Another showed a conscious aim to take on work that she would find stimulating.
Justine's mother was concerned that I was using people with learning difficulties to improve myself. She was reassured by my emphasis on the co-researchers getting something out of it too. It was important to value the co-researchers' input (a point made by Atkinson, 1988, regarding respondents). I hoped the experience would be enjoyable, and that they would learn new skills and gain respect and self-esteem. Nevertheless, I would be getting a research degree and I wanted the co-researchers to get something tangible too. I raised £750 from local organisations, which the co-researchers decided to donate to Hackney People First. My financial request also lead to a computer access company helping the group develop their use of technology. This consideration seemed more important to me at this early stage than to the co-researchers. For them, the newness, challenge and fun seemed to be enough; what else they got out of it did not become an issue until later (as discussed below), when the money was a distant memory.

One result of the consent and negotiation process was that the one man withdrew. He listened very politely and asked lots of questions, then quite firmly said no and explained that he was too busy. Powerlessness and susceptibility to pressure were clearly only one side of the picture! So the co-researchers were Justine, Susan and Betty - three very different women in terms of age, race and culture, but all with the common experiences of being labelled as having learning difficulties, being involved in self-advocacy, and living with their families.

3. The relationship between the co-researchers, myself and the research

This section addresses the overarching question of building the research relationship. My principle was that for co-researching to work there had to be reciprocal trust; I had to expect no more of them than I was prepared to give of myself.
Getting to know the co-researchers and the research

Attention to details, such as the meeting place, was important to ensure a sense of trust. We started meeting in a community centre which they had all been to before, was free, and was easy to get to. Once the venue started to charge we moved to meet in the co-researchers' homes. We all met together as a group for the first time two months after the process started; a fairly informal meeting to start to get to know each other, make clear what we were doing and plan out our work over the next few months. As well as talking, we did activities aimed at helping us find out about each other and develop trust. These included choosing the words which describe us, and drawing a picture of ourselves and the things which are important to us (Further Education Unit, 1992; Something to Say Project, 1987).

This was followed by a meeting on 'what is research?'. This comprised brainstorming and discussion about the meaning of the word, the purpose of research and different types of research. We practised interviewing and recording using different styles. It was a fun session in which we all learned: the co-researchers some familiarisation with research, myself the appropriateness of different techniques, and all of us learned more about each other.

We agreed a series of meetings to discuss self-advocacy and families and then go on to plan the research. The titles for the meetings were, 'what is self-advocacy?', 'living with families', 'self-advocacy and families', and two meetings on 'planning the research'. Through this process, the co-researchers and myself together developed our ideas and were able to look at the issues in depth. As will be discussed in the following sections, they helped set the criteria for the research, worked with me to develop the questions, set down guidelines and principles, and co-designed the research.
Trust, understanding and ownership

The behaviour of researchers is considered one of the most disempowering elements of traditional research methods. Feminists and others have emphasised the quality of the relationship, accountability and commitment, as crucial in the qualitative research process (e.g. Oakley, 1981). Applying this to co-researching, I paid particular attention to building the relationship, and the way I behaved was central in this. I encouraged open discussion and criticism. In terms of disclosure, I tried to give as much as the co-researchers, and aimed always to do what I said I would do. The co-researchers took the lead on my contact with their families and staff. We kept in touch between meetings with phone calls, reminder notes, and informal coffees. We went out for meals and Christmas drinks, and we all got invited to Betty's parties.

To avoid tokenism and get real involvement, I used a number of methods. At each meeting, we had an agenda with pictures up on the wall, which was produced by me but was contributed to by the co-researchers, both at the previous meeting ('What shall we do next time?') and at the start of each meeting ('What else?'). The notes that I sent to them after each meeting used their own words with pictures. I tried to use a mix of different methods in the sessions - brainstorming, drawing, listening to and recording tapes, putting key points on stickers and sticking them on charts, putting discussion points on bits of paper and pulling them out of a hat. All exercises were used with individuals' needs in mind.

Personal stories and feelings were shared. The co-researchers felt able to talk, and we all trusted our commitment to confidentiality (a fact which clearly was not the case in other aspects of their lives). The co-researchers often talked through things together, frequently by-
passing me. There was real listening, time given to allow people to talk, and positive suggestions or supportive comments made.

It was important to develop a sense of momentum, direction and progress. Each time we went through the overall plan of the sequence of meetings, and early on made a poster picture of the route of the whole research process so we could chart our development. This poster became known as the Yellow Brick Road (appendix 2). Each meeting had a looking back and looking forward element. The pace was quite slow as I was only a part-time student. Although in many ways this was appropriate, it also sometimes meant a loss of momentum. Inevitably, the sense of progress was up and down, but meeting informally in between meetings helped to keep the momentum going.

We had many overt discussions about control. The co-researchers developed a sense of ownership over the research. They began to refer to themselves as 'research people'. The answer to the question 'Whose research is this?' changed over time from 'Yours' to 'Ours as well'. The co-researchers rang me between meetings to keep a check on what I was doing or to make suggestions. There was clearly a sense of pride and importance: they spoke about the research elsewhere and gave it priority over other things. The question of overall control is returned to later in this chapter.

This section has discussed the overarching question of avoiding tokenism and building the relationship between the co-researchers, myself and the research. The chapter now sets the experience against the participatory research scheme in chapter 4. The following sections deal with the involvement of Justine, Betty and Susan in key aspects of the research process.
4. Involvement in theory

Participation of people with learning difficulties in use and generation of theory is either not discussed in the literature or considered very difficult (Stalker, 1998). My work is a contribution to making this possible. We had two co-researchers' meetings on background issues, one on self-advocacy and one on families. I shared my reading with them, and endeavoured to learn from them as experts on learning difficulties, families and self-advocacy.

In the self-advocacy discussion, I wrote the main points from my reading on stickers for the co-researchers to sort in order of importance and then stick on charts. This was used as a basis for discussion on what self-advocacy means and to which areas of life it applies. The families discussion began with a framework of basic issues from my reading, and used an audio tape (Open University, 1984) to start us off. We then talked about our own families, drawing relationship maps, and our own experiences of becoming an adult. In order to encourage sharing, it was important that I divulged as much of my own history as they did.

The co-researchers contributed a different perspective to that of most literature on families, which tends to focus on the perspective of the parent or sibling. Many accounts by people with learning difficulties are about leaving home and independence (see chapter 2). The co-researchers' discussion went further than this. They looked at stress, coping and support, issues usually seen in the literature as only concerning parents. They discussed the stress of family living, coping strategies, and the support to be found among friends at the day centre.

It was striking that the complexities of families and relationships were understood. For example, there was discussion of how difficult it must be to be a mother and recognition that changes are hard for parents. There was sophisticated analysis of why people feel the way
they do: 'I don't hate my mum but it's all the tension coming out'; 'It's frustration. I'm jealous. I want someone to love, to be there for me.'

At a later stage of the research we specifically discussed theory. My aims were to introduce the word 'theory' and that I would need to share some of my ideas with them; to show that they use theories in small ways all the time; and to gradually introduce complex words so that if I used them in later meetings they would have come across them before. We talked a lot about what theory is, defining it as ideas that help us to explain and understand things, and discussed theories in everyday life. I made a chart to show theories on different levels. This lead to discussion on space and time, racism and sexism, class, differences between people with learning difficulties and other disabled people. They started saying 'Well, my theory is...'

While this discussion was by no means easy, I believe it was correct to do it. Theory is a difficult area for many people, with learning difficulties or not, often simply because it is unfamiliar. There is such a mystique around academia that many people assume they could not possibly understand, whereas with some application they probably could. This must be the case for people with learning difficulties as well, at least within the limits of cognitive ability. I also assumed that while as a general rule it is correct to produce simplified versions of writing for people with learning difficulties, the need to avoid jargon is because it is unfamiliar, not because people are \textit{de facto} incapable of understanding the words and concepts. Many people with learning difficulties use concepts like 'over-protection' and 'community' - 'big words' which they use because of familiarity in service parlance. Always simplifying everything could continue the exclusion of people with learning difficulties from more demanding tasks.

This section has discussed the steps forward taken in this research in involving people with learning difficulties in theory.
5. Planning and design

This section demonstrates how the co-researchers made a significant input into the planning and design of the research, from setting criteria for self-advocacy and families and providing the basis for questions, to choosing methods and setting rules.

Setting criteria

The meeting on self-advocacy and families was the opportunity for people with learning difficulties to set their own criteria for the research (Barnes and Wistow, 1992). The discussion made me think afresh about self-advocacy and families and raised points which became significant in the interviews with respondents (for example, the difficult balance between the right to privacy and the need for parents to understand self-advocacy, an issue discussed in the findings chapters). The result of the discussion was a list of criteria for the research: what the co-researchers thought self-advocacy and families should be about (appendix 3). These criteria were the basis for the questions that were asked of respondents, and were also used in analysis.

Choosing methods

I had some doubts about this stage beforehand. It was something of a test: how much did the co-researchers really understand? Again I presented the main points of my reading and we had a free-flowing discussion about what would be the best way to find out about self-advocacy and families. I brought into the discussion my experiences from pre-piloting and preliminary discussions with self-advocacy groups (see chapter 6). It was a high-spirited meeting in which the co-researchers made excellent contributions and clearly understood
what was happening. The Yellow Brick Road was particularly helpful in showing the threshold we were about to cross.

The meeting came up with a plan for the research, which was to be piloted. They felt they wanted the research to be about getting to know people, taking time, building trust, and not putting people under pressure. This matched very well with my wish to do in-depth interviewing. The plan is discussed in the chapter 6. One of the things they were firm on was that they should do some interviewing, and after much deliberation Justine and Susan decided they should try some on their own.

Setting rules

The co-researchers decided on some research rules. They each threw in ideas, which I wrote on slips of paper, which they then took in turn and discussed, keeping some, rejecting others. It was clear that the co-researchers felt responsibility and saw the research as a serious task to be done properly. Most of the rules were intended as a control on me, as it was anticipated that I would do most of the interviewing, but at this stage they were also planning to do some interviewing themselves and so these rules were reminders to themselves as well. The rules focused on control, confidentiality and treatment of respondents: issues that would normally be called ethics (appendix 4).

This (and the previous) section have demonstrated the significant involvement of the co-researchers in the background and planning stages of the research. The next section goes on to discuss the change that took place in the research relationship when it came to piloting the plan.
6. Fieldwork - change in the co-researching relationship

This section discusses the changes in the co-researching relationship, showing the fluidity of the experience and raising issues regarding the reality of impairment.

After eight months of background work, we reached the pilot stage. Two of the co-researchers said they were not sure they wanted to continue. When we started I had not known what to expect, but I knew that their concept of time-scale might be limited and that we were not on the same journey. Nevertheless, it still came as something of a shock. I met with them individually, and it transpired that they both wanted to stay involved, but had changed their minds and did not want to do any interviewing themselves. I put to them the idea of forming an advisory group, and they liked this proposal, re-affirming their wish to stay involved in a smaller role. They both chose to be called 'consultant'. The decision was then taken to the third co-researcher, who was happy with it.

This change from co-researchers to consultants had a positive side. It was part of the whole process of movement and change, with its positives and learning opportunities. They still felt committed to the research. They had been involved for eight months and had made an invaluable contribution. They had seen it through the background issues and planning stages - if they were to change their roles it was an appropriate time.

Later, they referred to this as the time when they 'bottled out', suggesting that carrying out face-to-face research was too daunting - an important point in considering ways of involving people with learning difficulties in research. No one can be expected to be an expert at everything and there must always be the option for people not to participate in some aspects of research. However, the question must also be asked whether it was this particular
approach to interviewing that made it daunting. Other examples of people with learning
difficulties conducting research have used perhaps a more manageable approach, such as a
postal survey (Townsley, 1995) or interviews with a set schedule (Whittaker et al, 1991).
Similarly, with analysis (as will be discussed in the next section), quantitative material could
have been easier to deal with.

The same arguments led to the conclusion to do both participatory and qualitative research
(and it was the conclusion of the co-researchers that the interviewing should be long-term and
relationship-based), but this experience suggests that these approaches are not automatically
compatible. While fully in tune with the principles of making the data collection less
exploitative for the respondents and more productive for the research, our experience was
disabling for the co-researchers. They could not fully participate and had to go through
feelings of inability and 'bottling out', which they may not have had from more traditional
methods. This returns to the question of the possible limitations of people with learning
difficulties because of their impairment. Does it mean people with learning difficulties cannot
do qualitative research? I shall return to this point again later. Alternatively, it could be that
the subject was too difficult - personal to them, and one which could challenge a way of life
and cross acceptable boundaries.

This change to consultant status meant a change in the model to which I was working. We
discussed what a consultant is. In this context, they were the experts on what is feels like to
be labelled as having learning difficulties. They were experts on self-advocacy and living with
families. Their role was to keep up-to-date, say what they thought of what I was doing, judge
my work by their rules and give advice. Figure 2 shows the changed model, with Justine,
Betty and Susan as consultants, one step removed from the research process.
Although the change to consultant status substantially reduced their involvement and meant that the fieldwork was carried out by me alone, it was done following the rules and plan they produced and with continual reference to them. The change made the long-term aspect of involvement more manageable, enabling them to stay on board for four years in total. They continued to see themselves as staying with the project until the end. The probability was that there would be change again, and although they maintained their stance on interviewing, I hoped to be able to re-develop their involvement in the analysis and writing up stages, as did in fact happen.

For a year we met three-monthly. My main concerns were to explain what I was doing in such a way that they could properly comment on it and ask questions, and to demonstrate how it was based on the work they had done. I brought to them all the work I did, and picked out the main issues and dilemmas. They commented and advised, for example, on methods of approaching respondents and interviewing people with communication difficulties. They
successfully argued for a smaller number of respondents (ten) than my supervisors recommended (twenty), because depth with each person was more important than rushing through a larger number. Betty put me in contact with one of the respondents, and played a large part in introducing us and helping us get started.

The change to being consultants brought with it difficulties. It was inevitable that interest would go up and down over a long period of time, but especially so when we met less often and the research was more obviously mine. There was still a feeling of commitment, but there were also some doubts raised. One of the consultants said that all we ever did was chat and that I never did anything. Their feelings were a product of the change and demonstrated quite clearly that they were conscious of the difference in control.

These comments also raise the question discussed in the previous chapter of the purpose of research. Whereas Hammersley (1995), a critic of many of the bases of participatory research, argues that research should just be in pursuit of knowledge, this experience demonstrated that that is insufficient. I could have told Justine, Susan and Betty that research was not necessarily about doing all that much, but that clearly was not good enough - they thought it should be! But in this case the changes were intangible and the end product was too far away.

This raised a number of needs: to discuss their feelings about the research; to ensure that what we were doing was interesting and enjoyable; and to take steps to make the outcomes more real and immediate. The outcome of these discussions was to start the writing process much sooner than I had originally intended, to produce a more tangible result. Writing, and then later starting on analysis, drew them back into monthly meetings and re-identification as co-researchers.
At the end of the fieldwork, Susan stopped her involvement, having been a co-researcher for three years, because she was no longer interested. She kept in touch, ringing occasionally for an up-date and having an input into the writing. Justine, Betty and I had a discussion at this stage about their involvement. We talked about our different paths and what we were each getting out of it. We agreed that after the analysis we would go our separate ways - my job was to write the thesis while they were writing their findings report, though I would help them do that.

7. Analysis

Involving people in analysis is considered to be particularly difficult (Stalker, 1998). Minkes et al (1995), with some experience of involving people with learning difficulties in research, admit to not yet finding a way of involving people in analysis. Goodley (1996) comments that it remains to be seen exactly how researchers can truly involve 'informants' in drawing conclusions. Thus the challenge was set to involve my co-researchers in analysis.

The initial problem we faced was the quantity of qualitative material. At the end of the fieldwork there were 75 interviews and visits, physically manifested in a mountain of paper and tapes. The co-researchers appreciated the enormity of the task but wanted to try handling some of the material themselves. We went through one interview, starting with listening to some of the tape. I used their criteria for self-advocacy and families as categories, wrote these on sheets of paper and stuck them around the room; we then went through the transcript, cutting it up and putting each point in the appropriate category.

This session enabled the co-researchers to learn some aspects of analysis: that the same point could fall into different categories; that their categories could be broken down; that there are
no rigid divisions but that people's lives are complex and contradictory; and that patterns emerge which lead to ideas about meaning. The process also showed that there was far too much material to deal with in that way - it took two hours to go through one interview. We concluded that analysis would have to be split into two tasks: that I would trawl through the data and pull out the main points, and then involve the co-researchers in interpretation. Unfortunately but inevitably this meant that I would put my own slant on the work before it reached them.

We discussed issues in interpretation, focusing around confidentiality and inclusion. Four of the ten respondents with learning difficulties were known to the co-researchers, and they had been interviewed on the understanding that what they said would be confidential. Their identities had to be disguised before I presented the data to the co-researchers. This was possible because their interpretation was one step removed from the material, but it would be a more difficult issue to resolve if co-researchers were directly handling the data.

Regarding inclusion, the co-researchers raised the question of whether we should invite the respondents to be involved in interpretation. This would certainly have been appropriate in participatory terms (and would have most directly taken up Goodley's comment regarding involvement of 'informants'), but it would have involved substantially more work. Unfortunately, I had to take the decision that though desirable, this would not be practically feasible within my restraints as a time- and resource-limited Ph.D student. This relates to the point regarding the fit of this type of research with some aspects of academic work. An article published from this work (Mitchell, 1997) and the co-researchers' findings report (March et al, in press) has been sent to respondents.
Interpretation was not a one-off occurrence, but took place in a number of ways. We arranged an analysis weekend, to spend two days immersed in the material once I had made it more usable. For each respondent I drew a life-map (these feature in chapter 6 as an introduction to the respondents) and wrote up the main points on to a chart of the co-researchers' criteria. I also presented to them my analytic files (see chapter 6), to spark discussion around themes. In addition to this intensive work, throughout the fieldwork I had taken issues, both of method and content, to the co-researchers for discussion. They produced a report of the findings and Justine co-wrote a conference paper, both of which were further stages of interpretation.

The co-researchers' involvement in analysis, throughout a period of over two years, added a whole new perspective to the experience of self-advocacy and families. Their contribution will be highlighted in the findings chapters of this thesis.

8. Writing and presentation

Making report-writing and presentation participatory is considered difficult (Ramcharan and Grant, 1994; Bashford et al, 1995). The co-researchers have written, with my support, an article on co-researching and a report of the findings. An issue raised by Walmsley (1997) is the question of audiences. She makes the point that in a team of women with and without learning difficulties writing a book, of which she is a member, the women with learning difficulties want the outcome accessible to other people with learning difficulties and the non-disabled women want the book to be of a type to be taken seriously by academics and policy-makers. This is a difficult issue to resolve. The work of the co-researchers is aimed at both audiences, though not without complication. This again raises issues to do with the reality of impairment and the nature of academia.
An article on co-researching

Writing an article on co-researching took a series of monthly meetings. We reviewed our picture-notes and picked out what they wanted to include. The co-researchers looked back critically, reflecting on their own development. I taped the discussions, transcribed them and read them back; three times they cut it and added to it. I had some input into the content and they asked me to make sure it 'sounded right'. I took this to mean that it was in grammatical English and said the things they wanted it to say.

At this time, the British Journal of Learning Disabilities (BJLD) put out a call for articles by people with learning difficulties. The co-researchers decided to submit the article to this journal, with the proviso that they would also try to publish a version of the article in places where people with learning difficulties would see it, such as the People First newsletter. This meant getting permission from BJLD and abridging the article so that it was appropriate for a newsletter. The article was accepted by BJLD (March et al, 1997), with referees taking care to make their recommendations for change understandable.

BJLD's response raised points about learning how to write, and getting an article that is both genuinely written by people with learning difficulties and that is good and interesting in its own right. To achieve a result took some discussion with the editor, as publishing such an article was new for everyone concerned. My role was as a 'go-between'. Chappell asks (1997) how much this affects the integrity of people with learning difficulties' accounts. By doing this are we 'normalising' - overlooking their learning difficulties and fitting them into a debate in which we have already set the rules? If the writing of people with learning difficulties is treated editorially the same as everyone else, is that denying the impairment? But if people with learning difficulties are allowed to publish writing that others would not, is that
tokenism? The publication of such work is new, these questions are only just beginning to be explored, and conclusions can only be tentative. My view at this stage is that learning to communicate ideas is just as important a part of research as discussing theory or choosing methods. People with learning difficulties will always be excluded if we always prevent them from learning. It is important to help people to communicate effectively and gain respect for their work. Nevertheless, we must guard against setting norms which go beyond effective communication, which we then expect people with learning difficulties to fit.

A report of the findings

The co-researchers produced an accessible report of the findings in order to make a contribution to the development of self-advocacy. We decided on a structure based on the picture-notes we already had, covering who was interviewed, how, the main themes and the co-researchers' responses to these. We aim to get the report published and available to people with learning difficulties, advocacy projects, services and other agencies (March et al, in press).

We had to consider how to ensure the report was both accessible and of value to a range of people, from people with learning difficulties to academics. Bashford et al (1995) argue for use of parallel text as a way of simplifying academic accounts. The value of this is that there is appropriate text for both audiences. The reader with learning difficulties is drawn into the main text and the point is made to other readers of the importance of making ideas accessible. However, this approach was not appropriate in this case, as the co-researchers were producing an original report not a simplified version of a report of mine. The more appropriate model was the work produced by People First London (e.g. undated a, 1994c).

Our report uses words and pictures all the way through. The authors recognise that even with
all the pictures and straightforward language, many people with learning difficulties will not be able to read it. The introduction therefore includes an appeal to people who can read to read the report to those who cannot.

Presentation

The co-researchers have made presentations to both people with learning difficulties and academic audiences. They did a presentation to their own People First group. This was their meeting; they set the rules and so determined themselves that this should be an informal event. I was to start off, using the Yellow Brick Road to explain the research, and then they would take over when they felt comfortable. In the event, I only spoke for a minute before the co-researchers took over, explaining the research process and what they were learning. The discussion was reported in the group's newsletter (Hackney People First, 1994).

The co-researchers have also presented to academics. Justine and I presented a paper to an academic audience at the 1997 International Conference on Human Rights for Persons with Mental Handicaps in Prague (Mitchell and March, 1997). (Susan had dropped out at this stage, and Betty felt unable to travel.) We prepared for three months, meeting weekly, basing the presentation on the co-researchers' report. Presentation at an academic conference means specific expectations, but we ensured that the paper we submitted was accessible: every page was an overhead, which comprised few words, large print and pictures. In my view, this did not represent a watering down of ideas, though it limited our ability to develop points. However, it did require clarity.

This was not the first time people with learning difficulties have presented at a conference. There was, for example, another joint presentation at the Prague conference. The contribution
of *this* work is in extending what has tended to happen previously in presentations made by and with people with learning difficulties. Walmsley asks, was the absence of presenters with learning difficulties at the 1996 Disability and Society 10 Years On conference due to the 'nature and limitations of the impairment', or 'lack of imagination on all our parts to enable them to contribute at the level of an academic conference'? (1997, p.74). She observes that often in presentations, people with learning difficulties make a personal contribution which is then interpreted by others, and always seem to be advised and prompted by others. She asks if this is a limitation of advisers and organisers or if it is a limitation inherent in the impairment.

Our experience in Prague partly answers these questions. Justine and I took it in turns to speak, reading from well-prepared, well-rehearsed notes, both making interpretative as well as descriptive points. Most of the questions at the end were addressed to Justine, which she handled confidently and without prompts. I therefore suggest that it was the assumptions of the organisers and not learning difficulty itself which prevented people with learning difficulties presenting at the conference to which Walmsley refers. Prague was successful because of thorough preparation, i.e. manipulation of the environment and removal of barriers. Was it also because Justine has only mild learning difficulties? That already is begging for the boundaries to be extended again. Justine is also a development worker, with experience of organising, drama and speaking, in addition to co-researching with me for over four years. Three years ago she 'bottled out' of interviewing, but she thinks that with the same chance again now she might try it. In other words, it is not just her innate abilities that matter but the confidence that comes from her experiences, i.e. it is a social question. Sanderson (1995) has written recently of the possibilities of developing self-advocacy opportunities for people who are profoundly and multiply disabled - a long way from conference presentations but demonstrating that the possibilities are always changing.
This chapter has discussed my experience of co-researching against the model and scheme set out in chapter 4. The model has been shown to require flexibility, but also to be eminently feasible. The co-researchers have been the experts on being labelled as having learning difficulties, being involved in self-advocacy and living with their families. Their involvement has increased my understanding of these issues and allowed them to explore issues themselves in a way they had not had the opportunity to before. As a result, for example, they have given a different perspective on families to that put forward by most of my reading, which has tended to focus on the views of the parent or sibling. These discussions allowed for a participatory literature review.

The co-researchers set criteria for self-advocacy and families and rules for the research. We discussed how to do research and practised different kinds of interviews and methods of recording. Building on this we drew conclusions about methods and jointly set the research plan. They kept an overview of the fieldwork and participated in many of the discussions raised in the next chapter in regard to respondents. They contributed to theory and participated in analysis, adding their own interpretation of the data. They have written about their experiences of co-researching which will contribute to the development of participatory research, and have produced an accessible report of the findings which will contribute to the development of self-advocacy. They have made presentations about their work to academic and other audiences.

On a personal level, the gains for the co-researchers have included new skills and knowledge, respect from others and increased self-esteem. It has been an experience which they have in the main enjoyed and valued. There has also been financial gain. The co-researchers have
received some public recognition from their article, report and conference presentations. Walmsley (1997) asks if, following involvement in research, people with learning difficulties go back to their previous lifestyles rather than going on to new opportunities. In our experience, Justine is now a development worker for a learning difficulty voluntary sector agency. She used her involvement in research to help her application and now uses the skills and the findings in her work.

There are two areas in which the research has clearly not been participatory: in commissioning and choosing the topic, and in carrying out the interviewing. It also remains the case that despite high levels of involvement and their vital contribution, the relationship between us has been unequal - I have been in the driving seat. This raises the question of whose research this is. Having made the decision to try co-researching, I immediately faced the fact that this was my Ph.D., so that no matter how much I worked to develop the co-researchers' control, the ultimate control was mine. The reality of this was never tested as the co-researchers never fundamentally challenged the direction of the research (though they did change the process, bringing forward the writing stage). Was this because we were all in agreement, or because they knew I was really the one in charge? As suggested in the previous chapter, this state of affairs is perhaps inherent in the academic context.

However, as also discussed in the previous chapter, it is important not to raise up one particular level of involvement as a pinnacle. The co-researchers explain in their article:

'There were times when we felt angry, sad or upset. Sometimes it was hard to understand. We felt a bit nervous and shy and we didn't want to do the interviewing. But we think that's OK. People should be able to do whatever parts they can. Researchers should think hard how to help people take part in every bit of the research. But you can't make people do bits they don't want to.'

(March et al, 1997)
We cannot be rigid: involvement is a process in which all sides will learn and develop. Of course it is equally important not to be complacent. A safeguard is the reflexive element of the research - the process I went through as a researcher in scrutinising my work, behaviour and motivations.

Several points have been discussed in relation to the reality of impairment. Following French (1993a), all limitations faced by people with learning difficulties cannot be removed through social manipulation, because the intellectual impairment does impose some limitations of its own. The risk in acknowledging this is the possibility of opening the door to the positivist paradigm, and becoming complacent in our efforts to include people. This is a live and changing debate and the boundaries are constantly expanding. Without denying the reality of the impairment, we can never say we have reached the limit of possibilities, operating as we do in an exclusionary, oppressive society which limits the capacities of so many people.

Academia is by nature an elite world, demanding intellectual rigour and excluding the majority of the population. Nevertheless, inviting the participation of people with learning difficulties opens up questions as to how we can enable that involvement to be real rather than token. Chappell (1997) asks if the marginalisation of people with learning difficulties within the disability debate is due to the limitation of learning difficulty or to academics' unwillingness to change. Should intellectual debate be manipulated to include people with learning difficulties? Or are the problems inherent in learning difficulty? My view is that the nature of learning difficulties makes their involvement difficult, but it is academia (including disabled academics) that chooses to exclude people.

Conferences should allow presentation of material in different formats. Our presentation at Prague was not of the normal type, being based on pictures and fewer words than usual, but it
still managed to deal with important issues. There should be a conscious approach to ask people with learning difficulties to write in edited volumes, as other writers are, and in journals, as BJLD has done. Steps should also be taken to ensure other material is accessible so that people with learning difficulties can have access to others' contributions, not just their own. For example, at Prague, the only two presentations people with learning difficulties had access to were their own. This does not mean stopping academic debate, but working out ways to make the main points easier to understand, perhaps with parallel texts in books or accessible hand-outs at conferences. The Social History of Learning Disability Conference at the Open University in December 1997 attempted to ensure that all presenters considered their mixed audience and tried to address everyone.

As indicated in the previous chapter, these steps require significant change. My own experience was limited by the restraints of my position. This goes back to questions of the relations of production. I argued in the previous chapter that academia is not compatible with emancipatory research, but I also suggest that making research participatory also makes substantial resource demands. Nevertheless, there are steps that researchers and practitioners can take to reduce the exploitative and disempowering aspects of their work and make research more participatory. My work has been an attempt to carry out participatory research within an academic context.

The next chapter looks at the qualitative methods used in this research.
1. Introduction

This chapter discusses the methods employed in this qualitative study. The centrality of a reflexive approach forms the basis of the chapter. In this context, reflexivity applies in three ways: 'other-awareness', i.e. awareness of the respondents; reflecting on the research plan and process; and being aware of the relationship between the respondents and myself as both researcher and person (Atkinson and Shakespeare, 1993).

The chapter therefore begins with an introduction to the respondents and their self-advocacy groups. This also has the practical function of helping the reader follow who is who in this and further chapters. Section 3 describes the plan for the research, which was based on in-depth interviewing with ten people with learning difficulties and their families. The plan is discussed reflexively, showing how the process had to be flexible and sensitive. The section also briefly discusses the analysis of the data.

This thesis cannot discuss every issue which arose during the course of the work. However, the key issues in an in-depth approach, as discussed by Booth and Booth (1993 and 1994), centre around the relationship established between the researcher and respondent. Section 4
focuses on that, looking at access, consent, getting to know people, exploitation, giving something back, joint interviewing and withdrawing. The final section examines questions of reliability, validity, replicability and generalisability.

2. Introduction to the respondents and the self-advocacy groups

This section introduces the respondents and their self-advocacy groups, to aid the reader with the discussion that follows. 'Other-awareness' is a first step towards sensitive interviewing and an empathetic approach (Atkinson and Shakespeare, 1993).

The research focuses on ten people with learning difficulties, six women and four men. The criteria for their involvement were that they were members of self-advocacy groups and lived with their families. I shall briefly describe each person and their family, and use a life-map to show the different activities and people in their lives. The descriptions of the ten people are then followed by a table which shows their group membership and a description of each group. The names of respondents have been changed and group names are replaced by letters ('A', 'B', etc.).
Christine May

Christine was 21 years old at the start of the research, a working class black woman living with her mother, Vanessa. Christine was a member of 'A' People First. Her older brother also lived with the family, though during the research he was working abroad much of the time. Her parents were divorced although Christine still saw her father. During the research she found a job as an administrative assistant for a learning difficulty agency and towards the end found a boyfriend.

Figure 3: Life map for Christine May
Esther Cohen

Esther was 60 years old when the research started. She was Jewish and at the start of the research was living with her 80 year old mother in a council flat. She attended a day centre. She was a member of 'A' People First, of which she became the chair, and of 'B' day centre user group, which she ran virtually single-handedly. Esther also went to a special club one night a week and had friends who visited her quite often.

Figure 4: Life map for Esther Cohen
Anita Papandreos

Anita was 15 years old at the time of her interviews. Anita lived with her parents, older brother, younger sister and baby brother. Her family was well-off and had a big house in a middle class area. She was born in Britain but was Greek Cypriot. She was bi-lingual, but had very little speech, using a communication board (the use of which she extended during the research). Anita went to a special school, and a mixed disabled and non-disabled youth club where Young People First took place.

Figure 5: Life map for Anita Papandreos
Katya Klein

Katya was 38 years old at the start of the project, living with her mother in a middle class area. Her father died when she was 13. Eva, her mother, was German and a retired social worker. She had an older sister and brother, both of whom were married with families. Katya had always had 'normal' jobs and had recently become a development worker on 'E' advocacy project. She was a member of 'D' and 'E' People First groups. Eva was on the management committee of Katya's project and attended group meetings. She was a friend of Katya's boss. Katya went to an evening class and a special unit of the Guides.

Figure 6: Life map for Katya Klein
Fazila Begum

Fazila was a working class Asian woman in her late 20s. She lived with her parents, brother and disabled sister. She attended a day centre where she was a member of 'T' user group, which she had just joined when I met her. Towards the end of the research she also had the opportunity to attend 'G' People First. She had no other activities. At home she was a carer, both for her disabled sister and her mother, who became ill during the research.

Figure 7: Life map for Fazila Begum
Tracey Barker

Tracey, in her late 20s, was white and working class. She was fostered almost from birth and was the only one of 13 children fostered or adopted by the family to still live at home. Tracey knew her birth mother, who had learning difficulties, but she died a few years previously. One of Tracey's sisters died during the research. Mavis, Tracey's (foster) mother, was a care worker in learning difficulty services. Tracey went to a day centre and three special clubs. She swam, had a boyfriend and went to church. Tracey was a member of 'E' user group, which she left during the research. In the past she went to 'E' People First.
Michael Banks

Michael had his 21st birthday during the research. He came from a well-off Jewish family. He lived with his mother, father and (at the start of the research) older brother, and had an older sister staying in Israel. He attended a college, from where he did work experience in an elderly persons' home. He also had an unpaid Saturday job at Somerfields. He was a member of a 'special' social group, 'T', which was run by its users. They formed a committee to plan the social activities and develop self-advocacy.

Figure 9: Life map for Michael Banks
Kevin Waluk

Kevin was a Polish man in his late 20s, living with his parents. He attended a day centre and was a member of 'B' user group, as well as taking part in other advocacy initiatives within the service. Kevin went to a special club, but apart from this spent most of his time with his family at home. Mr and Mrs Waluk were known as fighters, battling for better services, taking part in consultations and developing something of a reputation in services. Kevin appeared to have taken on their fighting spirit, taking up various empowerment opportunities.

Figure 10: Life map for Kevin Waluk
Daniel was a mixed-race Asian/white, Muslim, working class man in his mid-20s. He lived with his father. His mother died when he was 11. He had a brother and sister, both married with children. He attended a day centre and at the start of the research was a member of 'F' user group, which he left. In his spare time, he visited his siblings and went for walks and bus-rides. He used to go to a Mencap club with his father, but they left. He had an on-off relationship with a woman at his centre.

Figure 11: Life map for Daniel Shah
Jason Cooper

Jason was in his mid-20s and black, living with his mother and father in a large house in a working class area. He had brothers and sisters who had left home and had their own families. Jason attended a day centre and had recently started working at MacDonalds three times a week. He attended a social club, but apart from this did not go out. Jason was a member of 'C' user group, taking part in a national project to change day services.

Figure 12: Life map for Jason Cooper
<table>
<thead>
<tr>
<th>group</th>
<th>respondent</th>
<th>adviser</th>
</tr>
</thead>
<tbody>
<tr>
<td>'A' People First</td>
<td>Christine</td>
<td>Sally</td>
</tr>
<tr>
<td></td>
<td>Esther</td>
<td></td>
</tr>
<tr>
<td>'B' user group</td>
<td>Kevin</td>
<td>Janet</td>
</tr>
<tr>
<td>'C' user group</td>
<td>Jason</td>
<td>Martin</td>
</tr>
<tr>
<td>'D' People First</td>
<td>Katya</td>
<td>Eliza</td>
</tr>
<tr>
<td>'E' People First</td>
<td>Tracey</td>
<td></td>
</tr>
<tr>
<td>'F' user group</td>
<td>Daniel</td>
<td>Sharon and John</td>
</tr>
<tr>
<td></td>
<td>Fazila</td>
<td>Sharon</td>
</tr>
<tr>
<td>'G' People First</td>
<td></td>
<td></td>
</tr>
<tr>
<td>'H' Young People First</td>
<td>Anita</td>
<td>Lisa</td>
</tr>
<tr>
<td>'I' social group</td>
<td>Michael</td>
<td>Simon</td>
</tr>
</tbody>
</table>

6 independent          7 attend independent groups
3 service-based         6 attend service-based groups
(3 people have attended both types)

Figure 13: Self-advocacy groups, attendance and advisers

'A' People First was funded through People First London, with a worker with learning difficulties and a non-disabled supporter, Sally. Esther became the chair during the research.

A quarter of the 16 or so members lived with their families.
'B' day centre group was run by Esther and Gavin. 'B' group had been supported by a health authority worker, Janet. Part-way through the research, Janet left and was not replaced. Half of the eight members lived with their families.

'C' user group was a day centre group of four members, taking part in a national project to change day services. Martin, a member of staff who played a supporting role, described it as a self-advocacy group with a fixed agenda. Half the group lived with their families.

'D' People First had Katya as secretary. 'D' group had links to services, set up for people in or moving out of hospital. Katya's mother was a great friend of Eliza, the adviser, and was also an adviser herself to 'D' group. Katya was the only member from around ten who lived with her family.

'E' People First was started for people living in and moving out of hospital. A few years previously, the group split (also creating 'G' group). Eliza set up an advocacy project supporting 'E' People First and user groups in services. Katya was the project's development worker. Tracey went to the group before the split. Katya's mother was on the management committee and often attended 'E' group. Half of the ten members lived with their families.

In 'F' day centre group Fazila became secretary. Tracey and Daniel were members (Daniel was secretary), but left. The members were elected from the centre planning groups. The two advisers were John, deputy centre manager, and Sharon, an independent advocacy worker. All but one of the six members lived with their families.
'G' People First was a split from 'E'. It only met bimonthly because Sharon, the adviser, was busy and the group could not yet function alone. The membership varied considerably, and I do not know how many lived with their families.

'H' Young People First took place at a disabled and non-disabled youth club. Anita was a member. Young People First was supported by People First London, and had a worker with learning difficulties, with a supporter (Lisa). All the seven members lived with their families.

'I' social club was run by its users, who formed a committee to organise social activities and develop self-advocacy. There was parental involvement, 'I' group having been established by parent pressure. All the twelve members but one lived with their families.

(The numbers of members are all approximate, as membership and attendance varied.)

3. The research plan and process

This section explains the plan of the research, designed between myself and the co-researchers, and the flexibility of its practice. A reflexive approach demands openness and recognises uncertainty about the likely course and direction of the work (Atkinson and Shakespeare, 1993). This does not indicate a lack of rigour. Careful planning is necessary in interviewing people with intellectual impairments, particularly about sensitive issues which cross boundaries between parent and adult-child, public and private domains. This section demonstrates the importance of both careful planning and flexibility.
The centre-piece of the research plan was a series of interviews with ten people with learning difficulties and their families. The methods used were piloted with four people with learning difficulties and their families, who were then incorporated into the main study. A life-story style was used to provide an overall context. This was followed by a more focused interview which looked more specifically at self-advocacy and families. There were also visits to self-advocacy groups, a parents' group meeting and interviews with group advisers. This section finishes with a discussion of the analysis of the data from this in-depth work.

Reflexivity requires, as Goodley says, 'being sensitive to our informants' and our own feelings, perceptions and speech' (1996, p.339). Atkinson (1997) comments how difficult it is to do this in practice. I kept a 'log', similar to Atkinson's reflective diary, to critically examine my performance as well as to reflect on what the respondents did and said. It was useful for both reflecting on the detail and possible meanings of individual events, as well as placing such events in a broader frame. The log was where I examined my interviewing technique after each interview, where I agonised over dilemmas, and where I started making connections and picking out themes. The log pointed to next steps and indicated areas I needed to take to others for discussion: to co-researchers, supervisors or supportive friends. This activity underpinned the research throughout.

The research plan

During the pilot phase I developed frameworks within which self-advocacy in families could be explored. These were based on my literature review, the co-researchers' criteria, and piloting experiences. Checklists and questions for each interview were based on these
frameworks (appendix 5). Thus the questions came from what people with learning
difficulties wanted explored.

a) Discussion in the respondent's self-advocacy group.

Atkinson (1988) found that group interviews helped to alleviate anxieties, that members could
help each other, and the presence of peers could serve as a check on the information.
Additionally, for me, visiting the groups was a chance to get a more rounded-out view of the
respondents' self-advocacy context, and a group discussion of families and self-advocacy
which could inform interviewing.

b) Get-to-know period of varying lengths.

Simons et al., (1989) stress the importance of a familiarisation period in order to be able to
understand people's lives and communication. I expected that this would vary between
respondents, sometimes taking place separately and sometimes alongside and part of
interviewing. Issues in getting to know and building the relationship are discussed in the next
section.

c) Interview person with learning difficulties four times.

The first interview was in an open style, starting from the question, 'What do you want to tell
me about your life?' Walmsley (1995) had the experience of one person who did not like free-
ranging questions because she felt vulnerable. In case my open-ended approach made people
feel uncomfortable, unsure how to start or guessing about what was really wanted, I was
prepared to talk about myself. A checklist was used as a back-up if the discussion ran dry.
Sensitive issues such as adulthood and identity were not raised in the first interview unless the
respondent talked about them. The second interview was loosely structured, using the checklist to ensure as many aspects as possible were covered. Interview three was on self-advocacy and families. As this was a more difficult subject, and in order to avoid leaving people floundering, I decided to make it more structured, with a flexible schedule. I considered giving the questions in advance, but discussion with the co-researchers suggested this would be too daunting and unnecessary in a long-term project. Interview four used a checklist to return to points for detail or clarification.

I aimed to use a relaxed style, but with precise wording and familiar, simple language, and to ask a series of simple questions rather than one long one. Atkinson (1988) favoured open-ended questions to avoid the pitfalls of acquiescence and recency. However, as Booth and Booth discovered (1996), open-ended questions can produce low levels of responsiveness, especially with people who are not very articulate. I therefore had to be prepared to break questions down. Booth and Booth's techniques of gradual elimination of alternatives and successive approximation to determine what a respondent means were both useful, though sometimes felt like interrogation. The risk of putting words in people's mouths had to be balanced by reflexivity and by the long-term nature of the research allowing me to get to know people.

d) Interview parent(s), try for three times.

These were to follow the same basic structure of a life story style first followed by more specific discussions on self-advocacy. I anticipated that parents would probably not need four interviews due to fewer communication issues; in practice the range was from one to three.
e) Interview adviser(s) once.

With the advisers, we planned just one interview with a schedule. This was partly because, although vital for back-up and context-setting, the advisers were not central to the research. The co-researchers and I also assumed that, unlike the people with learning difficulties and probably the parents, they would not need a long-term trust-building approach. They would be used to a formal approach, to discussing the topic and, importantly, were not talking about a personal matter. We also had to consider the time-scale and resources.

f) Joint interview with person and parent(s).

Atkinson (1988) found joint interviewing useful for seeing the dynamics of relationships and roles. I attempted them also to attain a new perspective. The next section examines some of the issues that arose in joint interviewing.

g) Parent group.

Towards the end of the research, the parents were invited to attend a parents' group meeting, to which four came. The meeting was to complement the discussions I had with innumerable people with learning difficulties in self-advocacy groups. The aims were to keep them in touch with the research, to get their response to the findings so far and to go deeper into issues.

Recording

My aim was to tape-record and transcribe, for thoroughness, as well as to make it easier to be informal. The tape was also a better way for people who could not read to have a record. I took notes when the respondent did not want me to record them, but this felt more formal,
and created a distance. Occasionally, when people started talking before I could reach for my tape-recorder, relying on memory and writing up after (as by Booth and Booth, 1994) made for a fairly accurate record. I gave respondents copies and checked back that they agreed with the record.

Flexibility

With this plan as a basis, the experience was actually fluid. The in-depth nature of the process allowed flexibility towards the needs of each respondent. I did not feel a need to fit everything in or to tackle questions in an order, or push issues beyond what people wanted to say at that time. The checklists and questions evolved throughout, as I reflected on each interview.

There needed to be flexibility with parents who were difficult to reach and only wanted to be interviewed once. The next section deals with questions of access and consent; the point here is that the plans had to be condensed in order to attain a sense of a life story, as well as some detail on self-advocacy, without seeming to rush through.

There are several examples of flexibility required with people with learning difficulties. I met Jason six times, weekly, because each interview was only about twenty minutes. He had a short attention span and tended to end interviews abruptly. I tried interviewing him without the tape-recorder in case that was putting him off. I showed him photographs of my family, job and home, which were successful in drawing him out more. I took the pictures from the What's On guide (Cragg and Garvey, 1990) to help us talk about control at home - he said, 'This is great this, I like doing these pictures'. I tried the same method again for going out and
hobbies and this time it did not work so well, suggesting that he needed variety. For the final interview with Jason, we went through self-advocacy questions like a formal questionnaire, which he seemed to enjoy, as if it were a quiz.

Communication skills were a particular issue with Anita. I met Anita seven times after first meeting her in her self-advocacy group. The first time, I had with me the pictorial representation of what the research would be like, and used this to ask questions, which she answered with sounds and gestures. When I arrived the second time, she had been thinking about the interview and arrived with pen and paper. It turned out she could read and write, though this was a physical struggle. I discovered that she had a communication board at school which she never took anywhere else, so I asked her to bring it with her next time, which she did, with a folder of extra symbols. The efforts she made suggest that the research became important to her. Another time I took the What's On (Cragg and Garvey, 1990) pictures to help me ask questions. I wrote everything down in notes, which she read as I was doing it to check I had got it right, though I used a tape-recorder as well so that Anita could hear her voice for the first time.

Analysis

The in-depth, long-term nature of the work generated a large amount of material: qualitative data from 75 interviews and meetings.

I anticipated that the impact of self-advocacy at home would be conditioned by a number of factors: the nature of the self-advocacy involvement; the level of conscious effort to transfer
self-advocacy to home; the experiences and attitudes of family members; and factors such as age, gender, ethnicity and class. I therefore planned to deal with the material in two broad areas, the self-advocacy context and the family context. Another significant area arose from the study: identity. There is therefore a grounded element to this work, that is the discovery of theory from the data (Glaser and Strauss, 1967). It is not possible to leave to one side entirely the assumptions with which a researcher enters a field, and it is in this regard that reflexivity is so important, but I attempted to allow my work to be shaped as much by issues that arose from it as by my assumptions at the start.

I explained in chapter 5 that the analysis was split into two tasks, the trawl through the material for themes and then interpretation. The first part of the process was done just by me, after an attempt with one interview with the co-researchers. I transcribed the tapes and did a basic content analysis as I went along (Weber, 1990). Following Lofland (1971), I then went through each transcript, picking out points and themes, creating an 'analytic file' for each theme. This process created 76 analytic files, which were then grouped into themes:

- self-advocacy issues (meaning, importance etc.)
- self-advocacy groups and their approach to families
- the translation of self-advocacy into the family (parental knowledge, privacy, perceived impact etc.)
- general family issues (history, impact of disability etc.)
- speaking up at home, according to the co-researchers criteria
- 'big' self-advocacy issues, such as leaving home, independence
- identity (adulthood, learning difficulty, gender etc.)
- change.
This material went through several phases of interpretation, both with the co-researchers and without them, including three separate stages of writing, re-grouping and applying theory. I interpreted the data according to the themes arising from people's own testimonies and against the criteria set by the co-researchers, and the claims and expectations arising from the self-advocacy and family literature.

This section has discussed the dialectical relationship between the plan, necessarily careful and detailed, and flexible practice, important in qualitative and empathetic work. I have also briefly addressed how the quantity of in-depth material was dealt with analytically. The chapter will now go on to reflexively discuss the research relationship.

4. The research relationship

A key issue in qualitative, in-depth work is the relationship between researcher and researched (Booth and Booth, 1993 and 1994). Atkinson and Shakespeare explain that a reflexive approach requires looking at 'research encounters, our interactions with the subjects and the building of research relationships' (1993, p.6). Trust and rapport have a bearing on the quality and validity of people's accounts:

'The actions and attitudes of the researcher must both validate the researcher's identity and what he or she claims to be doing as well as show that the subject is valued as a person in their own right'. (Booth and Booth, 1993, p.48)

I support the view that without trust people are unlikely to allow a researcher into their private lives. The establishment of this relationship is discussed here in terms of access, consent, getting to know people, flexibility and exploitation. I also discuss particular points in relation to joint interviewing, which itself throws up a number of issues.
Access

Gaining access was the first step in establishing a relationship, and so had to be done with care. I address here the main issues which arose in accessing respondents: using intermediaries, the length of time involved, and access to parents.

Walmsley (1995) writes of the potential pitfalls but also the necessity sometimes of going through intermediaries. I wanted to avoid having to ask the permission of other people to reach the person with learning difficulties. It is not easy to reach people directly, as many people with learning difficulties have staff and families as 'guards'. I ruled out attempting to reach people through home addresses - services could be unwilling to relinquish addresses and telephone numbers, and it would put too much power in the hands of parents. As the project was about people involved in self-advocacy, it made sense to go through self-advocacy groups. Using the London People First list, I contacted key individuals in the groups in my locality, aiming to visit the group if appropriate (i.e. if there were people in it who lived with their families and if I was welcome). Finding groups had a snowball effect - I was put on to others through the original contacts, including service-based groups.

An alternative route I tried was to ask advocacy workers to suggest particular people. This left my request open to their interpretation. Some paid attention to my explanations, and suggested names and how best to make contact. Others, however, contacted people themselves, discussed with their families as well, and then came back saying they had no-one interested. Much more successfully, one of my co-researchers suggested one of the respondents and facilitated our meeting.
A feature of this work was how long it took to do things respectfully, waiting for discussion and consultation within groups before being able to visit. It was important not to rush the process. Some groups were hard to get to - particular people (including those with learning difficulties) gate-kept or were very forgetful. Some groups were swamped with visitors and wary because they were always being asked to do work for other people. In total I visited eleven groups.

Access to parents

When I began, I asked people about meeting their parents as part of the initial discussions. I soon abandoned this approach, because agreeing to let me talk to their parents required a significant degree of trust which took time to develop. Self-advocacy and families is a difficult issue in itself because it crosses boundaries which perhaps people are not ready to cross, and people with learning difficulties may have felt uneasy about my spending time with ‘the other side’. Confidentiality and confidence in me were important. Anita, my fourth respondent, wanted us to get to know each other before I contacted her mother, and I then instituted this as the general practice.

I did not meet the Begums or Waluks because Fazila and Kevin did not want me to. Fazila said her parents' English was not good and there were no brothers and sisters at home to help translate. Having got to know her, I wondered also about the attitude her parents would have had to the research and whether her refusal was in order to avoid trouble. Kevin said he kept things to himself. I spoke to the manager of his day centre (where his group took place), and she confirmed this. He had been engaged in many user-involvement opportunities and his
parents had expressed concern about his level of commitment and the effect it had on him at home. But there was the additional issue of service interests clouding the matter: the manager said that work with the family was difficult and they felt they were having a breakthrough at that time which they did not want put in jeopardy. It was important in establishing trust that I should not force the issue.

This raised the question of how important was the parent perspective. Did the research with that individual still stand without the parents? I decided that it did, given the discussion in chapter 4, but the parent would have added an important aspect. Not reaching two parents unfortunately meant that my research fell victim to the age-old problem of only reaching the people that were keen and not those who perhaps had problems with self-advocacy. It also could have affected their son's or daughter's involvement - for example, Anita (whose mother did eventually get involved but took a long time to agree) felt at one stage that there was no point in her carrying on if her mother was not doing it.

In all cases bar one the mothers were the principal carers (three were sole carers) and I spoke mainly to them. I interviewed Mr Shah as the sole carer. I managed to interview two other fathers as well, but two I did not see at all: I never met them and there was no evidence of their being interested.

Consent

Consent was another important factor in establishing the relationship. The consent issues raised in regard to co-researchers in chapter 5 were also important in finding respondents.
The main issues that arose in regard to consent with people with learning difficulties were the question of power, making the research understandable, and the length of the consent process. Parents were harder to persuade and to pin down once they had agreed. Issues for them included the value of taking part and whether or not they knew about their sons' and daughters' self-advocacy involvement.

Edgerton, in the 1960s, explained to people with learning difficulties that they did not have to talk to him, but 'frankly, I doubt that they believed me' (1993, p.xv). Many people with learning difficulties might be conditioned into answering questions no matter who asks them and without expecting to have privacy. I could also see that no matter how hard I tried some people would never really understand what I was doing. However, as suggested by Walmsley (1994) and Stalker (1998), and shown by my search for co-researchers, people are not just pliable victims. In fact, it was not easy persuading people with learning difficulties to take part in research. It was unfamiliar to them and it certainly did not grab many people when I first explained it. I preferred to have people volunteer after group discussions; when I did approach people directly, two turned me down.

I followed Booth and Booth's (1993) assumption that when people had agreed to see me their commitment was conditional. After group meetings, I arranged to chat to volunteers on their own. I explained research as gathering information, finding out something new so that we could learn from it, and perhaps support self-advocacy better in future. We talked about what it would be like - when, where, how often, etc. - and that I would try to ensure as much control for them as was possible within my constraints. We talked about what they would get out of it - that it could be enjoyable, a chance to talk, and it would be a chance to contribute
to something which would help others. Walmsley (1995) had an information sheet to aid explanation. I used a pictorial representation of what the research could be like (appendix 6). I also used ideas such as showing them my tape-recorder, or showing them what research looks like in book form. It was not easy explaining - after discussion, Katya asked, 'So is it a self-advocacy group you're setting up?' To Jason, I described what I wanted to do as 'some work', and then had to explain that I was not trying to get him a job!

As with other aspects, the process of consent changed throughout. Katya and Eva Klein were my first respondents. Both had been interested when I met them at 'E' group. I spoke to them on the telephone later and arranged to visit to explain the research. I then arranged to go back again in two weeks for the yes or no, and then made arrangements to come back a third time to start interviewing. This lengthy process was later shortened. This was partly to reduce the risk of losing potential respondents, but also because I started to feel that the longer process was not necessarily helpful, possibly leaving people to make a decision with insufficient understanding or information. Perhaps it would be easier to decide if I was there and they could ask me questions. Leaving them to think could also have built it up into something more daunting than necessary.

With Anita I did not offer to go away to let her think. She agreed after discussion to be interviewed and made an arrangement for me to come back to start. Later, I shortened the process further. I arranged to meet people to explain the research, and when they agreed to be interviewed, I did so there and then. This meant I interviewed them while they were keen, but it might also have meant I pushed them too quickly. They had no opportunity to reflect. It
also carried the risk of reducing the time I had to get to know people, so I tried to ensure that I interviewed them several times so as to achieve the same depth as I reached with the others.

Consent from parents

A number of factors made parents the hardest of all to persuade. Unlike the advisers, this was not part of their job, and in their comparatively isolated circumstances they were unlikely to have such an overview. Most importantly, the subject was much more private, much more a part of them, their identity and their whole life. Clearly for parents there was a lot at stake. There was also the fact that the people with learning difficulties were to a large extent self-selecting, whereas the parents were then under pressure to agree. A particular sticking point was the value of doing research. For example, Christine reported that her mother was sceptical at the start about the value of what I was doing, but over time, as I worked with Christine, she started to see the value and wanted to get involved.

One consent issue with three parents was that they had no knowledge of their son or daughter’s self-advocacy group. I had to take particular care in dealing with this, to maintain trust in the research relationship. I discussed it with the people with learning difficulties first. With two people, they did not mind their parents finding out from me. Both these families proved to be positive about their son or daughter having privacy, were not worried that they had not known, and were immediately supportive of self-advocacy. These people obviously knew their parents well! This still raised the question of the impact of research: the introduction of new knowledge and the effects this could have had on family dynamics. In Daniel’s case he did not want his father to know about the self-advocacy group, although he
was fine about his being interviewed (which I think demonstrated his trust in me). I put the research to his father in more general terms, talking to him about the impact of the things people do when they are in the day centres, and about getting people's own perspectives instead of just that of professionals.

**Getting to know people**

Simons *et al* (1989) urge a familiarisation period in order to be able to understand people's lives and communication. This was very important in my research, though it did not occur in a fixed fashion. Getting to know people was sometimes clearly separate from interviewing, for example, chatting over a coke at a youth club, but usually the two were blurred (as with Stalker, 1998).

Booth and Booth (1993) argue for honesty and reliability. Taylor and Bogdan (1984) recommend paying homage to respondents' routines, establishing what you have in common, helping people out, being humble and acting interested. I attempted to put these into practice as much as possible (though I preferred to be interested rather than just act it!). I gave people control over the place of interview as much as possible.

Atkinson (1988) took gifts as a mark of respect, to value people's time and contribution, and to help set an informal atmosphere. I bought people drinks where appropriate and gave thank you cards at the end. Interviews started with talking about what we wanted each other to know about ourselves. I told them a bit about myself and they usually talked about themselves quite readily, with the level of my questioning variable depending on the articulateness and
readiness of the respondent. This reciprocity is good practice within qualitative research (Oakley, 1981; Shakespeare et al, 1993).

The people with learning difficulties showed signs throughout of becoming more confident and more in control, for example, switching the tape on and off, reading my notes, or setting time limits. Anita did a deal: 'I'll tell you more about me if you switch off the tape and tell me about your boyfriend!' They became confident enough to ask me questions, comment on my life and even give me advice. To help this confidence, it was useful, where possible, to talk about things they were the experts on, for example, Katya talking about Guides. Developing confidence was the case for some parents too. For example, when I arrived for the second interview with Mrs Banks she was much more relaxed. I had sent her a summary of the first interview which she enthused about. She talked much more easily and introduced new information, which I think showed how the relationship had become more based on trust.

Exploitation

One of the purposes of my qualitative approach was to try to overcome the potentially exploitative nature of research. However, occasionally the research did feel exploitative: I arrived, got someone to pour their heart out, and then left. They had no control over what I did with the material. The slightly rosy, 'It's great to have someone to talk to' approach of Finch (1984b) was found to be too easy by Walmsley (1995), who had respondents who later regretted opening up. Some of my respondents said they had probably talked too much, suggesting that they may later have regretted their level of disclosure.
There were many examples of people enjoying and appreciating the process. I have generally been seen as a genuine and welcome person. Three parents said they never said these things to other people (Mr Banks said, 'You know more about me than anybody else'). I have usually been thanked for listening. With several of the people with learning difficulties I felt conspiratorial, confidante-like. With Tracey's parents there was a sense in which this was an occasion. They were waiting for me - Mr Barker came out of the door as I came up the path and Mavis said she had been thinking of 'doing a Joan Collins'. Mrs Cohen appreciated talking, saying to me, 'You're the only one who will do it'.

Unfortunately, there are also examples of people not enjoying it. When I rang Mr Shah about a joint interview, he became angry, saying I was being like a social worker - he had been interviewed in good faith, now he did not know what he had got into. He obviously wanted a detached event which he had no part in other than to answer questions. In retrospect, I can see that I overlooked this.

Giving something back

Some respondents expected 'something to show for it'. I began by giving back a transcript. Katya's mother, Eva, appreciated it, but handing over a lengthy document to people with learning difficulties felt inappropriate. I went to great efforts to help people understand and then I gave them a tome to read. I wanted to value them, I wanted them to feel they had some control, and I wanted them to have a concrete result, something they could keep and show others. However, I felt it was off-putting giving them a transcript, maybe making people feel inadequate or threatened. Katya did not read hers; Christine tried to and stopped. Instead I
decided to give back a tape, which was much more successful. Tracey listened to her tape as soon as I gave it to her. Esther listened to hers on her head-phones when she went to bed. Others did not want anything at all. I continued giving a transcript back to parents and advisers, until I bumped into one of the advisers who said how embarrassed he was when he read his. I then started to give a summary or a tape, unless they particularly wanted a transcript.

What else did they get back? In a small way the research has contributed to change for some of them. Anita now uses her communication board at her youth club and in People First; Esther felt that the research was part of the accumulation of confidence which helped her to make life-changing decisions; others have appreciated the opportunity to make sense of their lives and to clarify ideas. Virtually everyone wanted to be kept in touch, as Katya said, 'Because we've put so much into it'. I have sent them published articles. In this way they can see how their part of the process has contributed to a bigger project, and while the changes which may or may not result from this are less tangible and a long way off, they can at least see publications to which they have contributed.

Daniel wanted help to discuss disputes with his father which were brewing beneath the surface. I explained that I could not solve his problems, but I could perhaps help them to talk. As has been discussed above, the attempt to arrange a joint interview with Daniel and his father backfired. This highlights the dilemmas around the purpose of research. Many of my arguments for participatory research centre on people wanting a result, wanting to see change, but that is not the case for everyone. Mr Shah wanted an event with no impact.
Joint interviewing

There are particular points in joint interviewing which require attention. Atkinson (1988) found joint interviewing useful for seeing the dynamics of relationships and roles, but also experienced the risks of influence, lack of confidentiality, and of people being ridiculed and humiliated. Booth and Booth (1994) also had mixed experiences. Their respondents felt at ease and sparked off each other, there was mutual prompting, cross-questioning and challenging, but the people without learning difficulties could dominate and there was a risk that the interviewer could collude in this, especially with the danger of using language that would exclude the person with learning difficulties. Bearing these warnings in mind, I attempted joint interviews to get a new perspective and see the dynamics of the relationship. Joint interviews took place with Katya and Eva, Michael and Mrs Banks, Esther and Mrs Cohen, and Christine and Vanessa. The other families wanted no more interviewing.

I raise joint interviewing in this section because there was a sense in which it changed the research relationship. I will use Katya and her mother Eva as an example. I got the sense that Katya felt she must have said something wrong when I asked her about doing a joint interview. She agreed but she seemed nervous, as if she was going to be exposed, or as if I was not on her side after all. In its favour, the joint interview meant we could focus on the issues that were central, and it led to new data. However, it was upsetting for both. Eva got quite angry and frustrated, and Katya became very defensive, evidently feeling under attack. I wondered if I left them more antagonistic than before. And was I actually impartial? Katya seemed to think I was on Eva's side and I could feel myself on the edge of Booth and Booth's pitfall of collusion (1994). Perhaps joint interviewing is not appropriate in work based on
relationships, particularly on an issue which crosses boundaries like this one. Joint interviewing perhaps requires special skills which are not usually addressed in the literature on interviewing techniques.

**Withdrawing**

In relationship-based research, Booth and Booth (1993) argue that withdrawing has to be done sensitively: people usually have a restricted network and the research relationship may assume great significance. Stalker (1998) points out the other side to this: why should we presume that people would want to make friends with us, or that this would be a problem if it were the case? Oakley kept in touch with some of her respondents (1981). In my experience this proved not to be an issue. Generally the respondents understood it should end. Some felt attached to the research, expressed a substantial interest, and wanted to be kept in touch with how the work progressed. Most of the respondents ended it very matter of factly. I sent them a card with the last transcript or tape and promised to keep them in touch if they wanted that.

This section has discussed aspects of the research relationship, demonstrating the need for flexibility, care and sensitivity in in-depth work. The next section looks at reliability, validity, replicability and generalisability.

**6. Reliability, validity, replicability and generalisability**

Sigelman et al (1981) raised questions of the reliability of people with learning difficulties as respondents. These arguments were addressed in the previous chapter. Carrying out long-
term interviewing allowed for checks internally: asking questions in different ways, repeating back what people said, and in the case of Anita, letting her read what I had written to check for accuracy. Returning tapes, transcripts or summaries allowed for another check, and in one instance a parent did make a couple of factual corrections to the notes. I could also compare between interviews and with other respondents, and make observations. Overwhelmingly my methods worked. In particular, the people with learning difficulties showed themselves to be reliable - stories were consistent and they fitted with what parents and advisers said and with what I saw.

Where there were potential problems, I was particularly careful. An issue with people with learning difficulties is that often they are not very articulate, the people Booth and Booth describe as 'not having much talk in them' (1996). My reflexive approach meant that I constantly examined my technique, asking myself, was I putting words in people's mouths, was I asking leading questions, was I talking too much? When I repeated what respondents said to check I had understood, they almost invariably said, 'Yes'; did they mean it, or had I actually changed what they had said?

There were times when there could have been recency and acquiescence. At times it was particularly noticeable that when I suggested a possible answer it was agreed to, and when I suggested a choice of answers the last option was agreed to. Again reflexivity was vital. I asked myself, are people echoing me, or saying what they think I want them to say, or getting confused by the same question being asked? On the other hand, it was also common for people to disagree or to correct me when I made a mistake. Overall these problems were dealt with through the long-term aspect and reflexivity.
In terms of validity, several people were not good on dates and times (though I understand that this is common for people without learning difficulties too). Talking about the past - especially for Esther, who was older and going through big changes - was not all that easy. Kevin could only give jumbled anecdotes about the past. But precision in the timescale was not what was important: my point was to get a feel for the person's life and context for their self-advocacy.

Esther also sometimes gave what felt like set-pieces, but that does not invalidate them - we all have our favourite stories (Atkinson, 1997). It was therefore important to keep checking and to fit what she said with other testimonies and observation. The long-term approach meant I could get to know her and her way of speaking, and it also meant I could see the changes she was describing taking place, so that there were constant reference points to real processes to help me understand.

There were sometimes contradictory answers. The issues I was trying to address were of a sensitive nature. To ask about control and choice at home, for example, could have suggested that there were things wrong in probably the most important relationships people have, and could have opened up all sorts of feelings. Inevitably, many of these would be contradictory. To ask someone if they are treated like an adult or a child could be felt as a direct challenge to their status and consequently their dignity and self-esteem. Sometimes it seemed that people were giving the safest answer first, or the answer which retained pride and dignity. For example, they would say yes they are treated like an adult, and then go on to explain situations where they had been treated like a child, or to describe how one parent treated them differently from the other. Sometimes what seemed to be contradictory answers turned
out to be explanations of change. Change was an important factor for all the respondents. For example, Christine was aware that she was growing up, and she said herself that her views and feelings kept changing. I was after feelings, thoughts, values, perceptions - these are not rigid things. Contradiction in this sense is not a sign of lack of validity.

Traditionally, research also uses such measures as replicability and generalisability. These measures are not appropriate for this research. This research was small-scale and relationship-based. Thus while the approach can be adopted by others and improved, it could never be possible to replicate and achieve the same results. Similarly, while some of the experiences of my respondents may be typical, there can be no intention to generalise from such a small-scale study. Barnes (1994) rejects these measures and instead argues for accountability, utility, consistency with values, accuracy, feasibility, propriety, perceived impact, and ability to achieve benefits. This research stands up well on Barnes' measures. It has been accountable all through to the co-researchers, is consistent with the values of self-advocacy, and has proved itself feasible. Accuracy comes from the in-depth, long-term, relationship-based nature of the research. The impact of the research has been examined reflexively. Utility and ability to achieve benefits are less easy to judge at this stage, though there have been clear benefits to the co-researchers and to some respondents.

The one area where I have doubts is in terms of propriety. Barnes does not explain what she means. It is a loaded term with moral and ethical overtones, and perhaps thus not a useful measure without more discussion. If by propriety Barnes means 'fitness', then I suggest a qualitative approach is correct for this kind of research. However, as discussed in chapter 5,
there were aspects of the research which the co-researchers found too daunting. In this sense there remains the question about the 'fit' of participatory and qualitative research.

7. Conclusion

This chapter has dealt with issues arising from the qualitative, in-depth nature of this study: reflexivity, planning and flexibility, the research relationship, and matters of reliability, validity, and other measures. It has demonstrated that the approach requires careful scrutiny and rigour in order to reach an understanding of subjective experience.

This chapter concludes the three chapters on methodology and methods. The thesis now turns to the findings from the research.
Chapter 7

SELF-ADVOCACY GROUPS

AND THE TRANSFER TO HOME

1. Introduction

This chapter is the first of three which discuss the findings from my research. I explained in chapter 6 that I anticipated that the data would fall into two main areas, the self-advocacy context and the family context, and that a third main area, that of identity, arose during the study. This chapter explores the first of these.

Two themes run through all three findings chapters. One is that of crossing boundaries. This idea is developed by, for example, Sibley (1995) to describe the boundaries that individuals establish for the purposes of identity and security, and that societies establish to maintain order. Boundary crossings are therefore significant events. The topic of self-advocacy and families crosses the boundaries between public and private, services and families. Taking self-advocacy into the family moves what has in the main been a service issue into the private family domain. I discuss the boundary between self-advocacy and home in this chapter. Studying this area in itself crosses boundaries, and is perhaps an explanation of why the co-researchers did not want to do interviewing, why two people with learning difficulties did not
want me to meet their parents, and why one allowed me to interview his father but not to
discuss the self-advocacy group with him.

Another, related, theme that flows through the three chapters is that of the difference between
the surface picture and the reality underneath. The respondents, both with learning difficulties
and parents, often initially gave 'public' versions of stories that were emotionally removed
from themselves, easy to tell and safe (as found by Cornwell, 1984). The depth of the
process, however, as chapter 6 showed, led to a development of trust which allowed more
personal, private stories to be told. The theme of the surface picture and reality underneath is
raised in this chapter in the distinction between principle and practice in self-advocacy.

The literature review in chapters 2 and 3 discussed the meanings of self-advocacy as to do
with 'all of life'. In its claims to autonomy and adulthood, self-advocacy challenges the social
identity of people with learning difficulties as in need of care and control and being like
children, and therefore has implications for families. However, the small literature on self-
advocacy and families suggests that there are few links made by those involved between self-
advocacy groups and families.

I argued that the deeply ingrained function of services to care for and control people with
learning difficulties means that their attempts to organise are themselves often subject to
control. This has meant a service orientation in self-advocacy practice and a lack of emphasis
on families. The literature review also demonstrated the importance of the adviser, in both
supporting and potentially inhibiting self-advocacy, due to service interest and the influence of
the individual model of disability. The advisers' role is under-researched (Walmsley, 1997) but
there are interesting points made by Goodley (1997 and in press). This chapter examines these issues of service influence and adviser roles in relation to my respondents.

I found in my research an apparently firm boundary between self-advocacy groups and home. Section 2 introduces this boundary and the difference between principle and practice. In section 3, I discuss the role of the adviser and the influence of services in the self-advocacy groups, finding that both are significant controlling factors in the practice of self-advocacy.

Section 4 looks at the attitudes and policies of advisers in relation to families. There is a tension between parents' 'need to know' about self-advocacy and the right of members of self-advocacy groups to privacy. The advisers often seem to deal with this tension by having very little communication with families. Advisers and service workers tend to see parents as inherently conservative, as barriers to new ideas. However, there seems also to be a fear and unease among advisers and service workers at the challenge of self-advocacy to their own roles, and they themselves may also find change difficult. The co-researchers suggest that the distinction between principle and practice could be put to good effect: that parents should be informed about self-advocacy, but not the details of groups.

The control exerted by the respondents with learning difficulties over the transmission of self-advocacy to home is explored in section 5. They do manage aspects of the relationship between the self-advocacy groups and home. Despite the little communication, self-advocacy has an impact at home. Section 6 continues the boundary crossing with a discussion of the reception for self-advocacy in families: the attitudes of parents to self-advocacy and its perceived impact. The parents I interviewed on the whole supported self-advocacy, and both
parents and people with learning difficulties were able to point to positive effects of self-advocacy as well as negative.

I use case studies to reflect the depth of this research. The participatory character of the work is central to it, and so throughout each of the findings chapters I indicate the contribution to interpretation of the co-researchers. In order to follow the names of people and groups in this and ensuing chapters, the reader should refer to the introductions in chapter 6.

2. Principle and practice

This section introduces an important finding in this research, that there is a distinction between the surface picture of self-advocacy and the reality underneath, and an apparently firm boundary between self-advocacy groups and families. I suggest that this situation is at least partly rooted in the ownership of and control over self-advocacy.

Chapter 2 saw the claims made for self-advocacy and the strides taken by the self-advocacy movement since its beginnings in the 1960s. One of its earliest proponents (without learning difficulties), Andrea Whittaker, has argued that the development of self-advocacy led to a profound change in service culture (1996). User involvement is now the order of the day and it is accepted by service workers that people with learning difficulties have the right to speak for themselves. However, there have been important warnings about service control (e.g. Dowson, 1990). Aspis (1997), a self-advocacy activist, quoted in chapter 2, raises questions about who controls self-advocacy and if it is really equipping people to make meaningful changes.
The findings of my research suggest that these warnings are well-founded. My respondents with learning difficulties all thought self-advocacy was important. Respondents talked about small and large decisions, and issues of independence and the whole of life. Their views of the groups, however, were different. For example, with Anita, the group got a shrug, while self-advocacy was very important. Daniel said speaking up for yourself was important but his group was not really working: 'Yuck,' 'It's crap'. Tracey said, 'I wasn't all that keen on it, I think I got a bit bored with it.' The distinction between principle and practice applies to several aspects, but the subject of this thesis is self-advocacy and families. This section discusses general points to show this distinction; the case studies in later sections will further illuminate them.

The respondents with learning difficulties thought self-advocacy was applicable to families. Christine, for example, explained self-advocacy thus:

'Something that happens everywhere I think. Probably in your job, in your home, probably with friends, probably going out. It happens in different places.'

However, the topic of families was not discussed in the service-based groups and was talked about but 'not much' in the People First groups. Only 'H' Young People First and 'J' group talked about families with any frequency.

The respondents with learning difficulties, parents and advisers all thought that parents should know about self-advocacy. The view of my co-researchers was clear: that parents' views were vital in determining how much could be translated to home, and even whether or not people could participate in self-advocacy groups. One co-researcher, Susan, said, 'They can easily stop you getting involved. They can just say "No you can't go".'
Information and understanding of self-advocacy would go a long way towards improving the ability of people to speak up at home. One of the co-researchers, Justine, explained:

'I talk to my mum about People First, and what I do there and what sort of things go on there. But she wants to know more about what they actually do, because I don't think she really understands.'

Parents would seem to agree. Christine's mother, Vanessa, said there was very little information available and should be more so that she could understand better. There is a 'need to know'.

But almost without exception, the groups had very little communication with families. The exception to this was 'J' social group, which had a significant level of parental involvement (I return to 'J' group in more depth below). I found that six of the ten sets of parents had only partial or no knowledge at all of their son's and daughter's membership of a self-advocacy group, and four of the ten had not heard of self-advocacy. There were differences between service-based and independent groups. The parents knew about the group if it was independent. The exception to this was 'Y' Young People First which took place in a youth club setting and therefore did not involve going directly from home. Parents did not know about the group if it was service-based. The exception was 'C' user group, which contacted parents as part of its wider project of changing day services. Parents knew about the principle of self-advocacy if their son or daughter was in an independent group. If their son or daughter was in a service group, they only seemed to know about self-advocacy if there was another context as well, for example, if their son or daughter also attended People First.

Thus, from my findings, although in principle self-advocacy means all of life, in practice the self-advocacy groups did not see discussing or relating to families as within their remit. These
findings support those of Simons (1992a), who found little direct link between self-advocacy and families. It would therefore seem that the boundary between self-advocacy and home is a strong one which it is not easy to cross.

An initial explanation for this difference between principle and practice could be that self-advocacy has been idealised and that the reality is simply more mundane. For example, Katya's mother, Eva, thinks that not matching up to claims is perhaps to be expected:

'[It] is sort of typical of any kind of organisation in many ways, which is that you subscribe to the philosophy but the way it's carried out is not -.'

Self-advocacy has had to be promoted and defended, especially in its early days, which would lead to a tendency to emphasise the positives (similar in some ways to the early evangelism of normalisation, see Chappell, 1997). It has been necessary, in countering the social identity of people with learning difficulties and the traditional individual model of disability, to demonstrate that people with learning difficulties can speak for themselves, and that they should have the opportunities to do so. Service workers have needed education and have had their practice challenged (e.g. by Cooper and Hersov, 1986; Dawson and Palmer, 1993). People with learning difficulties have needed their sights raising, as well as practical suggestions as to how to get started (e.g. People First London, undated a). Perhaps inevitably, then, there has been an evangelistic tone, and perhaps equally inevitably, the reality is less glowing.

It is also to be expected that an idea conceived in the abstract will not run smoothly when carried out in real life. This seems to be what one day centre manager meant when she said:

'What you hear is not what you get. We can all spout it but it doesn't mean we do it.'
Self-advocacy groups vary, family experiences are heterogenous, and people with learning difficulties and advisers are all different in their abilities and motivations. It is for this reason that my study has looked for the subjective experience in its context, and a dialectical materialist approach demands a recognition of diversity of experience and the real situations in which people and their ideas operate (Marx, 1963).

However, there is more to the split than 'inevitability'. Simons (1992a) looked for possible reasons within the self-advocacy context, suggesting that the focus of groups was services, that people with learning difficulties saw self-advocacy as 'their thing' to be kept private, and that there was little contact between self-advocacy and parent groups. In my research, there was no evidence of contact between self-advocacy and parent groups (such as Mencap). Both the other reasons suggested by Simons are echoed in my findings. Confirming the discussion in chapter 2, ownership appears to be disputed, and control to rest significantly in the hands of advisers and with a service interest. This is not the only factor at play, however: the people with learning difficulties I interviewed did exert control, particularly in the area of maintaining privacy and taking self-advocacy home.

The chapter moves on to address control and influence in the self-advocacy setting.

3. Families as a subject for self-advocacy - the role of advisers and services

Chapter 2 discussed the particular oppression of people with learning difficulties, and the pervasive influence of services. The role of the adviser was also discussed, particularly how important it is that the adviser should be independent (Dowson and Whittaker, 1993).
Walmsley (1997) comments that their role has been very little studied. My work therefore makes a significant contribution to the understanding of the advisers' role in self-advocacy. Drake (1997) proposes three roles for non-disabled supporters of the disability movement: exposing disabling aspects of society, supplying resources and responding to requests for help. In chapter 2 I suggested a fourth: that because of the oppression of people with learning difficulties, they would often need help to get started, to learn skills and have their sights raised. I return to these suggested roles at the end of the next section.

Goodley (1997 and in press) offers a useful analysis of the advisers' role, arguing against stereotyping because of their structural position, and emphasising their model of disability and approach to empowerment. He also points out the determination of people with learning difficulties themselves in supporting self-advocacy. My work suggests that the self-advocacy experience is shaped by both structure and agency (of both advisers and people with learning difficulties).

I found differences between the service-based and independent groups, but in all cases the advisers had a very prominent role in determining the topics of the groups. The specific background and circumstances of the adviser were factors, but the influence of services was particularly significant. Dowson (1990) warned of various ways that services could try to control or undermine self-advocacy, including setting up groups, choosing who does and does not go, and deciding what the group talks about. I shall illustrate these by using the example of 'F' user group.
'F' user group

'F' group takes place in a day centre, meeting once a week. Daniel Shah, Fazila Begum and Tracey Barker were members of 'F' group. Daniel was a member of the group for six months, including being the secretary, but then left. Tracey replaced him as secretary, but she also left the group. Fazila had just joined at the start of the research and soon became secretary herself. The group's advisers were John, the centre deputy manager, and Sharon, a worker on an independent advocacy project (herself with a service background).

'F' group was set up by the new deputy manager, John. The centre was organised in planning groups, and John established a system whereby each planning group elected one person to go to the user group. The representative was meant to canvas the views of their planning group, bring them to the user group, and then report back. This was intended to be democratic, but in practice it was the opposite. In this way, the service determined the structure and subject of the group before it even began. As Stalker found with the adviser in her case study (1997), John saw it as his role to set parameters:

'One of the initial problems we had was that it was very hard for them to grasp not to bring personal issues into it. So very initially, a person would say, "Oh, so-and-so pushed in the dinner queue," and we'd say, "Right, now, have you a problem with this particular person or does it affect everybody else?" And the guideline that we finally gave them was that if it affected a lot of other people in the centre then an issue should be brought to the group. And if it was only a one-to-one thing, then really they needed to sort it out with their key-worker.'

This approach put people on the spot and would make it very difficult to raise problems such as bullying. Unsurprisingly then, the issues the group discussed were all what John described as 'in-house':

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'We had a shower along the corridor here that didn't have a lock on it. They wanted a lock on it, they got it... The new curtains that are down in the hall, they had a moan that they had light in their eyes when they were having dinner - new curtains appeared.'

John seemed to trivialise issues group members raised, presenting them as 'moans', which could give the message that raising personal issues was risky. Meanwhile, he presented the service as very responsive - things just 'appeared'. However, he also gave examples of similarly straightforward issues which were not dealt with so miraculously:

'One of the on-going things at the moment is about locker space here. The building we have is very small, and a lot of people have these massive bags with goodness knows what in them... You can't get 500 bags in a locker. But try and explain that rather than have bigger lockers, and they go, "Oh, I don't know about that!" So that's one we're pretty much stuck on and we're still tackling that one. You know, "If you didn't bring your six bags you wouldn't need bigger lockers".'

Here John was clearly taking the side of the service, expecting the users to change rather than helping them to campaign. These are precisely the problems Dowson and Whittaker warn against when they argue for advisers to be independent (1993). John knew about his conflict of interest:

'There probably would be more issues come out if there wasn't a staff member there.'

But even though there was another adviser, Sharon, from an independent advocacy project, he hung on to his role. When I asked him about this, he said that he would leave when he considered that the group was ready. He seemed to be holding on to his 'baby', perhaps making his job more interesting, or boosting his reputation as a progressive manager. Perhaps he was afraid, as Crawley (1990) says, of letting go and seeing it all go 'wrong'. It is also possible that the service wanted to keep him there to maintain control.
Sharon had a very different approach. Rather than simply ruling out 'personal' issues, or describing the in-house questions as 'moans', Sharon analysed what people raised to find the issues. For example, bullying was an issue which should be taken up across the board, not an individual thing to be brushed aside. She believed collective action was needed to really make changes, and was not so ready to portray the services in a favourable light. For example, in regard to the curtains in the dining room, which John said just 'appeared', Sharon described the group as having to argue for something which should have been there in the first place:

"In the dining area it's a very big room, a big hall and it's mainly glass. There were no blinds, no curtains, and people used to sit there and fry all through the summer every year. You go anywhere else in the local authority or staff offices, there's blinds, there's curtains or whatever. It's massive, the only way I can describe it is it's like a fish tank. And when you bear in mind that there's a lot of people who do suffer from things like epilepsy and migraines, it's really a gross oversight. So they went to the manager, they got a catalogue and quotes of how much things would cost and said, "Look, we really want this"."

Sharon was open to discussing family issues, seeing it as a way of showing her commitment, and suggesting that curtailing discussion was a sign of detachment. But the discussions she described took place informally, not in the meetings themselves. Even Sharon, despite her independence and her different approach, described the group as service-oriented:

"It is about them evaluating their service and then giving their views about what's happening on a day to day basis in that service."

This was perhaps in part due to her own service background. Sharon was aware of John's conflict of interest, but felt unable to resolve the problem:

"John is perceived by the group as being a member of staff - although he's a very approachable member of staff he's still a member of staff, and he still has a conflict of interest in that group. And I actually feel it will be easier for the new chair to grow into her role as chair if he wasn't there. And I'm really, at the minute, in two minds whether to say what I feel to John. And I don't know what the group feel either, the group may say, "Yes, we want John to stay"."
She did not know what the group thought - there was no evidence that she had asked them. Sharon was susceptible to service influence, and her position as an independent worker was unable to counter the effects of the service (as Stalker found in the group she studied, 1997).

This service influence was reflected in the way its members talked about the group. According to John, the group belonged to the members, he described it as 'their group', and seemed bemused by his observation that the members did not see it this way:

'Because when we asked them who was running the group, they said, "It's your group," which kind of defeated the object.'

Fazila evidently wanted the group to be about the issues she thought were important, detailing to me precisely the issues John ruled out, such as people shouting at her. But she then went on to describe the group purely in a service context:

'We got a curtain, we got a fan, two fans, we got all the stuff we need... All the groups go back, to feed back, they want talk and feed back to us. We talk about all the group, different planning groups, and feed back.'

Daniel similarly saw the group as about centre issues:

'Problems in the centre. Talks about things that goes on in the centre. And see what can be done...'

Tracey said family issues were not to be taken to the group:

'If you've got any problems, you go to your instructor, if you've got any problem, and they write it down in your book.'

Fazila was conscious of the difference between Sharon and John. Sharon helped with the tasks:

'She does writing for us, and we get a chance to do typing and computing.'

John, on the other hand, had a staff role:

'John does writing down all the minutes, he does that too, so what happening, and he feed back to all the staff.'
Fazila had problems with John as an adviser. She thought he did not listen or understand, and was wary of saying things in the group that he might pass back to staff. The members did not seem to see themselves as able to do anything about this, however.

Due to the election system, Daniel was actually in the group against his will:

'Because the person who used to do it stepped down. So my instructor asked, when we were in the planning group one day, asked if anyone wanted to do it. Well nobody wanted to do it, I mean I didn't even want to do it. But I got lumbered because nobody put their hand up.'

Daniel described the group as boring, as did Tracey. They both found the tasks expected of them too much. Tracey explained:

'It was just boring all the time... I think it was about taking things back to your planning group, which I didn't do... Because I might have been too frightened to tell the planning group.'

Here the service was placing an expectation on the group members which they did not want or felt unable to fulfil. Daniel found the group 'too much work,' 'It's a chore'.

Daniel also felt under pressure from some of the staff and other users. He was angry that the group was not understood and that instead of being helped he was being criticised:

'Well, one of the reasons why I stepped down from the group is to do with my instructor. I don't like her that much. Sometimes I don't like her attitude to the group. The planning group came up to the 'F' group once and they said it was a bitching session. And that really annoyed me... So I stopped going, because that really upsets me.'

This point echoes one of Crawley's findings (1988), that while certain staff supported self-advocacy and set up user (then called trainee) committees, these groups were generally unsupported and even sabotaged by staff in the centres.
In 'F' group then, it was, in effect, the service controlling the group and what it could talk about. John kept the agenda firmly on service issues. Even then, he stifled the discussion, defending staff and then reporting back, and perhaps creating an environment in which people felt vulnerable if they criticised too much or raised difficult issues. His presence prevented honest discussion because of what Sharon perceived as the group's loyalty to him. Sharon was unable to counter the effects of the service. Group members did not see it as their group, found it a chore, and were even in it against their will.

I have used 'F' group as an extensive case study to illustrate issues of control in the service-based groups, confirming the warnings of Dowson (1990). I indicated above that the independent groups were different in their attitude to families. Nevertheless, in the People First groups there were still influences from services and differences of perception and control. I use 'A' People First as an example.

'A' People First

Christine May and Esther Cohen were members of 'A' People First. The group was supported by London People First, funded independently of services, with a person with learning difficulties as the adviser, and Sally as supporter (who did not come from a service background). Unlike 'F' group, everyone was a member by choice, having been recruited from local services. The group met once a fortnight on a Wednesday evening in a community centre, and no staff were involved.
Nevertheless, the influence of services was demonstrated in the subject of the group. Sally said, 'They can talk about what they like', but:

'People tend to be more focused on their services than they are on their families.... It depends what people are having problems with.'

It is possible that services were simply seen as more of a problem. Both Esther and Christine said the members could talk about families, and Esther did talk about her difficulties when she was trying to leave home. However, Christine said she did not talk about families and would not want to in the group. She made the point that 'you have to be careful what you say about your family because other group members could use information against you'. I return to the question of privacy below. The point I wish to make here is that this comment is reminiscent of Chappell (1994) in regard to friendship. Services divide and isolate people with learning difficulties from each other, preventing friendships from developing and undermining any sense of commonality. An effect of this may be that 'A' group members did not feel they had trusting relationships with each other.

Despite valuing 'A' People First for the skills she could learn from it, Christine had severe reservations. Throughout her childhood she went to mainstream schools, and though she had extra help in the classroom, she was never labelled as having learning difficulties until she left school. She went to college to retake the exams she had failed in school, and was put into a training scheme. It was there that she first came across People First. For Christine, attendance at People First was her step into the learning difficulty world, the first time she had been segregated, and the first time she had been openly identified by others as having learning difficulties. Chappell (1994) makes the point that there is a difference between the imposed segregation of a service and the self-segregation of a self-advocacy group. However, this does not take into account the reality of many self-advocacy groups and the way that they are
over-shadowed by the service setting. To Christine, People First was firmly part of the service system. If she wanted to get back to a normal life, she would have to leave the group:

'Because I feel that People First has got nothing really to do with what I'm going to be doing in the future, how I'm going to be living and what I'll be doing. Like they say that the sort of person you are now, is like, gives you a good idea of the sort of person you're going to be in the future. I think that's not really going to help me in the future.'

Thus even in an independent group like 'A' People First the service influence was pervasive.

To Christine, People First was like a service, it was labelling and segregating.

The study of these two groups indicates differences and similarities between service-based and independent groups. I suggest that the influence of services in self-advocacy is such that even in independent groups both advisers and members assume services are what it is all about. The experience of 'A' group suggests that attempts of people to self-organise are not only controlled and/or influenced by services, but are tainted with the negativity that services inflict. The oppression of people with learning difficulties also means that they appear to be socialised into assuming that it is not up to them to decide what happens in the group. This leaves advisers in control, setting the tone, so that the groups deal with what the adviser thinks is important.

The other side to this is that the respondents with learning difficulties did actively regulate their experience, a point made by Goodley (in press). I return to this issue of people with learning difficulties' control in section 5. The fact that services have such prominence probably means that people want to talk about them. And perhaps group members do not want to talk about their families in the groups. There is certainly a lack of trust, perhaps due to the break-
up of relationships, fear of what might get back and a lack of real ownership over the meetings.

In 'A' People First the sense of adviser control seemed less overt. However, in the discussion in the following section of attitudes and policies towards families, the role of the adviser can still be seen to be fairly decisive.

4. Crossing the boundary to home - adviser attitudes and group policy towards families

Thus far this chapter has discussed the control and influence over self-advocacy groups. This impacts on whether people with learning difficulties see the group as a place to discuss the topic of families, or feel able to use the group to deal with family issues. I now turn to the attitudes and policies towards families. There was a lack of communication between the groups and the families, despite the general acceptance of parents' 'need to know' about self-advocacy. This section looks at this from the point of view of the role of advisers; section 5 looks at the role of people with learning difficulties. It is useful to return to 'F' user group and 'A' People First.

'F' user group

John held some stereotypical views of parents. He gave many stories of parents restricting their adult children (apparently without seeing the restrictions he placed himself). He believed that parents see their sons and daughters as children, that they protect them too much, and often see them as permanently limited and incapable. Much of this, he said, was down to fear
of risk-taking (echoing Simons, 1992a). He also believed that part of the problem was that parents do not see their adult child's progression, again echoing Simons' (1992a) and Wertheimer's (1989) view that parents are kept at arm's length by services. However, he put this down not to the fault of the services, who 'make every effort', but to 'the parents not being interested'. Despite holding these stereotypical views, John believed that parents need to know about self-advocacy. He said:

'I think we should plonk them down and say, "Your Johnny isn't five years old anymore, he's forty two..." I think we need to teach the carers.'

John here was doing what Simons (1992a) says staff do: casting the parents in a villain mould. His starting point was that the service had it right, the parents had it wrong, and the service needed to teach them. But he did not 'plonk them down', he passed on no information and continued to keep them at arm's length.

Sharon, with a different tone, argued that parents and professionals all need to learn together about self-advocacy:

'I think if you remove it too far away from the families and professionals, it's like, "We're going to move at this speed but you've got to stay where you are".'

In her advocacy project, Sharon gave out a basic information sheet for parents, but made few other attempts to reach them. Her rhetoric was different from the reality. Perhaps, as with John, she saw the group as so much to do with the day centre that she expected it not to have an impact on families. Certainly the parents of Daniel, Fazila and Tracey did not know about their involvement in F group.
Sally, the supporter, made an effort to view things from the parents' perspective, rather than assuming stereotypes:

'They find it hard to accept that their son or daughter is growing up anyway, it is hard to accept them making decisions and having a say about things. Speaking up groups can be seen as quite a radical thing. So parents are going to be quite sceptical, I suppose. They're going to think, "Oh no, are they going to be trying to radically change everything, are they going to come home and totally challenge everything I do?" So it's probably a natural reaction to say, "Oh my God, they're changing their whole lives". And people find it hard to change anyway.'

(I turn to parents' views in section 6.) Sally thought parents needed to know about self-advocacy:

'I think there's a need for parents to be aware of what self-advocacy is, and that everyone has a right to say what they feel about things and speak up for themselves, I think that's important, and they should know that's what the aim of the group is. But they shouldn't be involved in the group, because that defeats the whole object of the group being a speaking up group and it being their space.'

But again, the work to help parents become aware did not happen. Did Sally believe that by avoiding letting parents know about self-advocacy she would prevent their concerns, or that at least she would not have to confront them? There is a suggestion here that too much involvement of parents would compromise the purpose of the self-advocacy group. This is an important point, indicating that advisers wrestle with dilemmas about what to do. Sally said, 'we don't have direct contact because we're there for the members.' This was a point also made by Lisa, the adviser of 'H' Young People First, who explained that if she worked with parents it would be compromising. Allegiances would be questioned and people would be less likely to talk about their parents in the group if they felt they could not trust the adviser. As a
consequence, in 'A' group, Sally did not see it as her role to help people take self-advocacy home, for example, in dealing with problems:

'It's not that we can't get involved but we don't get involved in that sort of thing. We talk generally about how they're feeling about it and then give ideas which they will then go and talk to their key worker about'.

Sally was concerned that her role as self-advocacy supporter should not be confused with that of a service worker. I felt there was a worry here not to be tainted by association. However, what it did mean was that Sally kept her distance, parents knew very little, and all involved felt they should know more.

I found no evidence of the people with learning difficulties discussing or even thinking about a group policy towards their families. Whenever I raised the question with the respondents as to whether parents should know more, and if so how, they always took it as a personal issue rather than considering a group approach. Esther, for example, showed her mother the notes from 'A' group occasionally, and said her mother knew about self-advocacy because she had told her. On the other hand, Daniel, in 'F' group, said his father did not know about self-advocacy, 'because I haven't told him'.

One thing this suggests is that the respondents with learning difficulties did not want a group approach, but wanted to maintain personal control over the transmission to home. I return to this point in the next section. It also indicates that a collective approach is difficult for people with learning difficulties to achieve and that control over the group is perceived to rest in others' hands. I suggest that this is a result of the oppression of people with learning difficulties, which has served to make it very difficult for people to organise. This leaves
control over policy in advisers' hands. Their attitude set the tone and their views decided policy.

The four roles for a non-disabled supporter suggested by Drake (1997) and myself at the start of section 3 would seem to be exceeded in these cases. The service-based adviser clearly had a conflict of interest and maintained his control in the interest of the service. But more broadly, advisers perhaps had assumed a greater role for themselves because the group members had intellectual impairments (Goodley, in press, suggests that supporters may assume incapacity). This is reminiscent of the comments of Baistow (1995) and Dowson (1997) regarding empowerment being different from taking power. The advisers encouraged group members to have control, but they remained in a powerful position and still had the ultimate control. I am not suggesting the advisers I met were deliberately saying one thing and doing another. They were well-meaning people, over-worked, under-resourced and doing what they considered to be their best. The fears they ascribed to parents they perhaps had themselves, such as challenges to their position and losing their role.

Goodley (1997) makes the point that self-advocacy would be better practised if advisers operate according to the social model of disability. None of the advisers I interviewed spoke in such terms. The groups certainly did not discuss any theories of disability, or discuss strategies beyond 'showing people what we can do', 'showing people that we are just like them'.

I suggest that advisers like John are operating to a traditional individual model of disability and pathological approach to families. He appeared to see the group members as inherently
limited in what they could do and the service as there to serve; in his analysis, families were seen without their social context, and were simply unable to adapt. In their efforts to empower people with learning difficulties and to understand families, I suggest advisers such as Sharon and Sally were reaching in the direction of the social model. Sharon, in 'F' group, was clearly constrained by the service setting in which she operated, and was probably influenced by her own work history. Sally, adviser to 'A' group, had fewer overt constraints but was nevertheless working in a general climate in which her work was associated with services in the minds of people like Christine (and perhaps even in her own). She also wrestled with dilemmas regarding her proper role which were not easy to resolve.

The dilemmas seem to centre around parents needing to know about self-advocacy, but the groups needing to maintain members' trust, and people with learning difficulties having the right to privacy. Through discussion with the co-researchers, we brought together this dilemma with the distinction between principle and practice. The distinction could be used to distinguish between parental knowledge of the group and of self-advocacy itself. I suggest this is what Simon, the adviser to 'J' group, was seeking to achieve.

'J' group

Michael Banks was a member of 'J' group, a social club for people with learning difficulties run by its members. The members formed a committee to run the club and develop self-advocacy. The worker with the group was Simon, who helped organise the social activities as well as facilitate the meetings. He came from a non-service background. Michael described 'J' group thus:
'We're all friends. We meet every two weeks, going out, staying in, which is what we want to do, it's up to us what we do... And it's a speaking up group.'

He said they talk about families 'if we want to', and the group listen and give advice. There was more discussion of families in 'J' group than in the others. Virtually all the members lived with their families and the subject of the group focused on social life, which necessitated dealing with families. Simon described the group:

'It's main aim is to allow people to have access to recreational facilities that are going on in the borough, to plan, to take charge of their lives. And breaking away from families and parents and taking control of their lives...'

Simon's use of language ('breaking away') may suggest an implicit assumption that families are restrictive, but the group members were all young adults, and there is also the suggestion that Simon saw this 'breaking away' as the same transition as all young people experience.

'J' group was set up by parent pressure for social opportunities and maintenance of relationships as young people became adults. Thus 'J' group was set up to respond precisely to that division and isolation to which Chappell refers (1994). In consequence, for Michael, there was more trust. Mrs Banks, Michael's mother said, 'They've all grown up together and he feels at ease.'

Because the group was set up by parent pressure, the parents felt an involvement. There were reciprocal phone calls with Simon and information which the people with learning difficulties took home. Periodically there were open events. Simon said:

'There's parents that know the project inside out... They all absolutely adore the principles behind what the project is trying to do.'
Mr and Mrs Banks knew about 'J' group and thought it was 'brilliant'. Mrs Banks knew about self-advocacy as well, but did not know the details of group discussions, seeing that as Michael's affair.

This relationship with parents could have brought with it the risks of which Sally was wary: conflict of interest and a lack of trust in the adviser. Simon was sensitive to these risks:

'As a group that is based on self-advocacy, which we promote, we always put the needs of the user first, and on joining the group, the carers and parents do have to respect that.'

The setting and history of 'J' group was clearly important here, but I suggest that again the outlook of the adviser was decisive. Simon could have pushed parents into the background, or he could have gone to the other extreme and fallen into the traps about which Sally was worried. Instead, he aimed for parents to know about self-advocacy, but also to understand the need for their sons and daughters to have privacy. At the same time, he aimed to ensure that the members trusted him and the group, and felt that it was theirs. For Michael this seemed to have worked: 'J' group was one of the most important things in his life, he described Simon as a 'good bloke', he talked about his family in the group if he wanted to, and he maintained privacy at home. The next section turns to the role of the respondents with learning difficulties in the transfer of self-advocacy to home.

5. Crossing the boundary to home - people with learning difficulties in control

This section deals with the strategies used by the people with learning difficulties to control the transfer of self-advocacy to home. Chapter 2 emphasised that in the face of control and
power relations, people with learning difficulties are not passive victims but do actively shape their experiences. The boundary between self-advocacy and home has been demonstrated to be a strong one. Simons (1992a) found that one of the reasons for the lack of link between self-advocacy and home was that people with learning difficulties felt self-advocacy to be 'their thing,' to be kept private. This section deals with the issues of privacy and the regulation by group members in the crossing of the boundary.

Trust in the group was discussed above. This in itself may be sufficient to keep discussion of families out of the groups. Perhaps families are just too private to be discussed in a group setting. Fazila, for example, explained that 'F' group was not the place to discuss private things; if she wanted to talk about her family she would do so one-to-one. In this we see not just lack of control over the group, but the people with learning difficulties actively deciding for themselves what they want discussed.

This becomes particularly clear when it comes to what people talk about at home. All bar three respondents with learning difficulties said they did not talk about self-advocacy at home. Tracey and Anita had not told their parents about their groups but were happy for me to do so, and their parents supported their involvement. On the other hand, Daniel, Fazila and Kevin did not talk to their parents about their groups and did not want me to tell them. The others did talk to their parents about self-advocacy groups, but only in a limited fashion, and still wanted to maintain privacy. Christine talked about self-advocacy 'sometimes': 'I don't talk about it that much, but I do talk about it', 'just to keep her informed.' There are different issues here: privacy was both wanted for its own sake, and as a strategy for managing the home situation. I look at two people's experiences to explore these points.
Esther was a member of both 'A' People First and 'B' user group. For Esther, her right to autonomy was all-important, and privacy was part of this right. Esther did talk to her mother about her involvement in 'A' People First, but not about the fact that she also chaired 'B' user group at her centre. This highlights that going to a People First group from home meant parents had to know, and some negotiation was necessary. Esther nevertheless wanted to maintain privacy. She sometimes showed her mother notes from the meeting and sometimes chose to discuss it with her, but at other times chose to keep things to herself.

There was conflict with her mother over this. Esther saw that she was maintaining her privacy by not divulging details of her meetings, but her mother perceived this as Esther not really understanding self-advocacy. Esther said:

'Not talking to her about what I done. I don't tell her what I do. It's my life!'

Mrs Cohen said:

'She doesn't tell me anything, she comes home from her meeting and goes into her room with her papers. I ask her and she says 'It's just a meeting'. She doesn't tell me what it's about. She doesn't know.'

Esther's tendency to keep things to herself seemed to me to be a challenge to Mrs Cohen's role. When Esther said, 'I don't have to tell you if I don't want,' her mother responded, 'How can I help you then? How can I be interested if you don't tell me?' This is an echo of Wertheimer's (1989) point that parents are used to being the only confidante, and find not knowing about some things difficult. Here there is conflict over the boundary between control by a parent and the autonomy of her daughter.
Kevin Waluk

Kevin was a leading member of 'B' user group. He did not want me to meet his parents. My information on their views comes from Kevin himself and Susan, his day centre manager. It appears that Mr and Mrs Waluk had a reputation in services as fighters and probably complainers. Susan’s explanation was that Kevin had a very concerned, articulate family, putting forward their own views along with other carers, and he seemed to have taken on their fighting spirit. In the past he had been involved in a number of advocacy groups. Susan said his family were not anti-advocacy, but they became concerned because he was doing so much. The meetings sometimes overran the time and that had transport implications. They felt that the groups were too much for him, he got too anxious, and so they ‘influenced him’ not to go. He carried on with ‘B’ group without their knowledge. When I asked Kevin about meeting his mother he said:

‘She's not interested really... I don't sort of say anything really to her, keep it to myself really.'

So, in contrast to Esther, for Kevin, maintaining privacy was a strategy to avoid conflict. It enabled him to continue with his self-advocacy activities, albeit in a reduced way, without his parents attempting to stop him. My co-researchers commented that:

‘...loads of people with learning difficulties have to do that - keep things a secret to get what they want.'

Kevin's and Esther's experiences were not everybody's. Some parents respected the right to privacy. Although Mavis Barker, Tracey’s mother, had not known about Tracey and 'F' group, she did know about self-advocacy because she was a service worker. She was fine
about privacy - Tracey was 'allowed secrets' and did not have to account for everything. Mr and Mrs Banks respected Michael's privacy, seeing it as normal. They know about 'J' group. Michael told them he could not talk about the meetings because they were private, 'So we'd say fine. We'd leave it like that.' The approaches of families to these issues are developed in the next section.

In the previous section, I explained that the co-researchers and myself suggest a distinction in the information parents receive, between knowledge about self-advocacy and knowledge about the group. This would appear to be what Christine May wanted. She kept tight control over what her mother knew about 'A' group, but was open to the idea of her reading relevant material, being trained and discussing self-advocacy with other parents. Esther also wanted privacy regarding both her groups, but when it came to self-advocacy as a principle, she wanted her mother to know. Daniel Shah did not want his father to know about his user group but he did want him to know about self-advocacy. The respondents with learning difficulties seemed to think that their parents understanding self-advocacy would enable them to maintain privacy, rather than cut across it. In the case of the Barkers and the Banks, above, their acceptance of privacy was linked to their knowledge of self-advocacy.

This section has looked at the control people with learning difficulties exert over the transfer to home. This is a question of rights, autonomy, and management of the boundary between self-advocacy and families. I next look at the reception for self-advocacy at home.
6. Crossing the boundary to home - the reception for self-advocacy

This section explores the attitude of parents to self-advocacy and its perceived impact. The advisers suggested that self-advocacy would not go down well in families. Where the control lies over daily living will be addressed in chapter 8. This section looks at the boundary crossing.

Simons (1992a) found no real hostility to self-advocacy among parents. Wertheimer (1989) found parents who were supporters, feeling that their sons and daughters had benefited considerably. One parent had set up a self-advocacy group. She also found concerns from some parents that self-advocacy may be developing too quickly, putting people in situations where they did not have enough skills. Some worried whether their child had a grasp of what it was about, and questioned whether people with learning difficulties were intelligent enough (reminiscent of Mrs Cohen).

My work confirms these findings. The case studies below illustrate the main points. Contradicting the advisers, the parents I interviewed generally said they supported self-advocacy, and were keen to receive more information so they could understand it and support it better. This does not mean, however, that they did not have reservations.

With some parents, the reservation was that while self-advocacy is a good idea, it did not apply to their son or daughter. There were reservations about the effects of self-advocacy. The previous section discussed how Kevin's parents were reported to support self-advocacy but had told Kevin to stop going to groups because of the stress they created for him. There
was an occasional sense from several respondents with learning difficulties that 'nothing really changes'. There were, however, many examples of positive effects of self-advocacy. Parents felt pride at their sons and daughters' new achievements. Some felt it helped them to speak up at home. Self-advocacy was seen as leading to more awareness, both political and self-awareness. Growth in confidence was commonly recognised at home.

I have chosen four examples to illustrate these points. They include parents who knew about neither the group nor self-advocacy, those who knew about the group but not self-advocacy, and those who knew about both the group and the principle. They include parents who supported self-advocacy and those who said their offspring could not speak for themselves. These examples highlight differences with the age of parents, class differences, and possibly also cultural issues. I explain some of the background to the families, but issues raised regarding family experiences will be addressed in the next chapter.

Anita and Mrs Papandreos

Anita was 15 years old, the second of four children all living at home, the youngest of which was just two years old. Mrs Papandreos and her husband came to Britain from Cyprus. The family was well-off, living in a big house in a middle-class area, and Mrs Papandreos had never had a job. Anita was severely physically impaired and had very little speech. Mrs Papandreos was her primary carer. She described a total life change when she had Anita. The effects were deep and permanent: 'something sticks inside and it never goes away'. Mrs Papandreos did not talk about her feelings and experiences to anyone, even to her husband.
Isolation was a striking feature of her life. The family were not happy with services and life was portrayed as ceaseless effort.

Nevertheless, Mrs Papandreos did not need to be encouraged to look for positives. She wanted Anita to have a good life and be independent. Mrs Papandreos was the only parent who appeared to have no reservations about self-advocacy, and yet she probably had the least knowledge. I think this was at least partly due to Anita's youth, so that the ideas Mrs Papandreos had come across through services were fairly modern. Anita was also a vibrant and frustrated teenager, making many demands, which must have impacted on her mother.

Anita valued privacy, and did not tell her mother about 'H' Young People First because it was her business (Mrs Papandreos did not need to know about it because it took place at a youth club). She did not mind my telling her, and Mrs Papandreos's response was:

'That's Anita's business, if she wants to tell me that's up to her. Anita has to carry on her life, she has to decide what she wants to do. Like this research, if she wants to talk to you it's up to her. I'm not going to stop her doing something she wants to do.'

Mrs Papandreos had never heard of self-advocacy, but she said Anita had to decide what to do in her life and she welcomed self-advocacy when she learned of it: 'People First sounds very good.'

**Michael and Mr and Mrs Banks**

Michael had his 21st birthday during the research. He came from a well-off Jewish family, the youngest of three children. His older brother still lived at home (at the start of the research) while his sister was staying in Israel. Mrs Banks had worked since Michael was fairly young,
and the family had always employed an au pair. Mr and Mrs Banks had been devastated when Michael was born, and spent the first few years of his life in and out of hospital. They had been disgusted with the health service and went private, but education and social services they thought had been good. They had support from the Jewish community. Mrs Banks' main concern for Michael was that he did not have friends he could go out with - she wanted this for him but also for herself, so that she would be happy for him to move on at some stage and she could have her own life.

Mr and Mrs Banks knew about Michael's membership of 'J' group and thought it was brilliant. Mrs Banks also knew about self-advocacy and similarly liked it. Michael said his parents thought self-advocacy was great. Mrs Banks confirmed this:

'Yes, definitely! If he doesn't want to do something he'll tell you. If he does want to do something he'll tell you… My other children do it, so why shouldn't he?'

'In fact it makes me quite proud to see him do it, that he's got the brain power to be able to say what he feels and what he thinks.'

Mr Banks did not know that 'J' group was about self-advocacy, but he supported the idea immediately, though with a rider: self-advocacy was Michael's right, as long as it was socially acceptable. He also suggested that Michael had learned to speak up anyway within the family.

'I think that's good, because he is entitled within his own limitations to be treated like another human being on a one-to-one basis. The fact that his academic levels might not come up to the norm and his behavioural pattern might differ from others, that doesn't mean to say he hasn't got feelings. He certainly has got feelings which need to be satisfied. And I believe he should be able to say what he thinks in his own way, within socially acceptable parameters. You know, I wouldn't like him to go along the street and drop his clothes just because he feels like it, it's got to be socially within normal disciplines. I believe he, like our other two children, learned to express themselves.'
Mrs Banks thought self-advocacy was in Michael's character, but 'J' group had definitely helped:

'I think it's character as well. I mean, you can have a quiet person, they won't necessarily speak up for themselves. But I think it's Michael's type of character to be independent and speak up for himself. But they've obviously brought it out and helped him.'

Mrs Banks had great concern for Michael's acceptance of his disability and sense of self. She thought 'J' group had helped with this. The group had also helped him grow in confidence. It offered Michael a social life, which his parents valued. In this way, 'J' group helped with one of Mrs Banks' main concerns, which in turn helped her to think more confidently about the future. Mr Banks said, 'without it people like us would suffer'.

At one point Michael said self-advocacy made no difference at home. I think this meant that he was generally satisfied and did not feel change was needed, because he also said the group helped him to speak up at home, and in fact would help him get what he wanted if his parents disagreed with him. Mrs Banks said that 'J' group had helped Michael more than anything else he did.

**Jason and Mrs Cooper**

Jason was in his mid-20s, but Mrs Cooper was older than most of the other parents. The Coopers were from Barbados; Jason was born in Britain. He lived with his parents in a working class inner city area. His older brothers and sisters had left home and Jason wanted to do the same. Mrs Cooper was the main carer. Her husband, she said, was a 'typical man', he never did anything! Mrs Cooper had been very upset when Jason was born. She thought
that professionals had been hurtful, and she had never trusted them since. She had felt isolated, and said that her friends and family were always asking after Jason but never her. She seemed very tired, and said she lived day-to-day. She hoped that one day Jason would marry and have a good life, but she made no preparation:

'I try not to worry so much anymore. I used to worry till it made me ill, high blood pressure. People talked to me, told me not to worry. It's now in God's hands. People make plans but God unplans them. There are other children much worse than Jason.'

The interpretation of the co-researchers was that she wanted him to get married so that someone else would take on the mother role and continue to look after him. They point out that:

'You don't have to meet someone to move into your own home. It's an extra barrier she is putting up'.

Mrs Cooper knew that Jason was a member of 'C' group, and part of a national project to change day services. She had received information from the project and from Jason. She knew the meetings were about users' views of changing day services and she did not want him to miss out. She was pleased that Jason knew about the changes and about government policy. She did not know about self-advocacy, however, and Jason had not told her. When I explained it to her, she thought speaking up was a good thing - but that Jason could not do it:

'Jason says, 'I want', but within myself I know there's not a lot he can speak up about at all. If there's anything he's got to say, he does tell you his mind at times, but you can't understand. He can't make decisions for himself.'

Jason may have known what his mother thought, saying to me he needed more help to speak up at home.
Katya was 38 years old, and lived with her mother, Eva, in a small house in a middle class area. Her father had died when she was 13. She had an older step-sister and a younger brother, both married with children. Eva was German, and had grown up under the Nazis. She remembered disabled people 'disappearing' when she was a child. As with the others, Eva had felt isolated and at a loss when Katya was young, especially because she was her first child and she did not know what to expect. Katya had meningitis as a child, but her difficulties did not emerge until she was growing up. She started in normal schools but moved over to special provision. Katya was still resentful of this, which was one of the reasons why she was determined never to go to a day centre and had always managed to find 'normal' jobs. Eva had never felt properly supported by services, and became a learning difficulty social worker with the intention of doing better. Eva retired during the research and was reflecting on her life. She felt tired. She had always worked hard to support Katya, but worried she had let her down. She felt Katya could have been 'a leader' had she not been disabled, and felt a great sense of loss.

Katya was a development worker on a self-advocacy project, which incorporated 'E' People First, and was also the secretary to 'D' group. Like one of Wertheimer's parents (1989), Eva was actively involved in self-advocacy. She was a manager of the project Katya worked on and attended both Katya's groups as an adviser. Eva had devoted a lot to self-advocacy - 'If the groups hadn't been in existence [Katya] wouldn't be where she is today'.
Katya said self-advocacy had helped her to develop skills:

'When you set up a new group you don't have a clue what to do. People give you advice and you don't know. Now I do.'

She believed she had learned, but also that she made mistakes:

'It's certainly taught me to say yes or - well, not so much yes and no, as when to use it. Not that I always use it at the right time now!'

Katya also believed that self-advocacy had developed traits she already had, similar to Mr Banks' view. For example, she thought she had always been a fighter, but self-advocacy gave her the skills to fight better. Eva said the self-advocacy groups had made Katya more focused and given her a philosophy: Katya now had views about the treatment of people with learning difficulties and demanded equal rights.

However, Eva had reservations. She believed Katya did not employ self-advocacy skilfully, and did not accept responsibility:

'I get really mad with Katya because she goes around in her own sweet way thinking she has a right to speak up, not realising that there's a way to do it, so people actually respond in a way she wants them to respond.'

'She doesn't see the other side, the responsibility, and that's very frustrating. She's not developed her skills as much as she could.'

Particularly frustrating for Eva was their argument about the future, in which Katya resisted making plans. I return to this in chapter 9, but my point now is that Eva expected Katya to use what she had learned from self-advocacy and believed she did not. After an argument, Eva turned to me and asked, 'What has self-advocacy done for Katya?'

'On the one hand she wants to be very independent, but on the other hand she isn't taking that independence seriously enough, or taking the responsibility for it. That is what in a way upsets me. Because she's got so many skills, but doesn't seem to recognise that she's got the responsibility to carry out those skills in a way.'
Eva was concerned that the self-advocacy movement as a whole has concentrated on rights at the expense of responsibility, and at the expense of teaching skills. This is an echo of Wertheimer's findings that some parents thought people needed to learn more skills (1989). It is also a reminder of Aspis's point that self-advocacy groups are not teaching the skills necessary to make real change (1997). Eva was clearly disillusioned that the rhetoric of self-advocacy was removed from the reality. However, neither she nor Katya seemed to see any conflict arising from Eva's own attendance in the groups, or any awareness that this itself might inhibit Katya.

These examples have shown the varied reactions to and effects of self-advocacy. Crossing the boundary to home is not a clear cut issue. As with Simons (1992a), I found no hostility to the idea of self-advocacy, though Jason's example shows that not all parents thought their son or daughter could do it. The response of the Banks could in part be due to the work of Simon in 'J' group to build a relationship with parents. It was also clear that up till this point there had been no real challenge by Michael which would upset the family, no need yet for anything to be renegotiated. There are similarities here with Anita and Mrs Papandreos - Anita's youth meant she and her family still had high expectations.

These examples show class questions: perhaps education, standard of living and expectations of life were also what helped the Banks and Mrs Papandreos to be so receptive. There are possible cultural and certainly gender issues in Mrs Cooper's expectation that women look after men, and that Jason would need to meet someone before moving out. These examples also suggest that the experience of different generations influence the ability of parents to accept self-advocacy. Mrs Papandreos and the Banks, younger parents - or perhaps more
importantly, parents of younger people - were more receptive than older, though Eva shows not all older parents are the same.

7. Conclusion

The distinction between self-advocacy in principle and in practice is significant. The principle says it should transfer to home, but the practice of these groups did not aid transmission. Despite the general recognition of parents' need to know about self-advocacy, there was little communication.

The self-advocacy experience was shaped by both structure and agency. In the self-advocacy setting, both control and influence by services and the role of advisers were significant. The advisers exerted more control than might be expected from the principles of self-advocacy - certainly more than the four roles suggested at the start of the chapter. I have considered Goodley's (1997) argument for advisers to operate from the social model. The advisers I interviewed were not consciously operating to any model, but some did appear to be inching their way towards the social model; however, the influence of services was a significant counter-weight. The advisers were pessimistic as to the impact of self-advocacy at home, and from their perspective, the transmission of self-advocacy to home was more a by-product than purposeful.

To the members, however, the transfer to home was a significant issue over which they exerted some control. This was partly in order to manage a conflictive home situation, but also a rights issue to have privacy and autonomy. There was an impact of self-advocacy
involvement at home, with some positive effects and responses from parents. Section 6 has suggested some of the factors in this.

The discussion shows that the distinction between principle and practice could be used to advantage, in order to distinguish what knowledge parents receive. Who does this and how is a matter that could be discussed within the groups. This would enable parents to know about self-advocacy without invading privacy, which could in turn give new form to the transmission to home.

The next chapter looks at the family context to discover the experiences of control and autonomy at home and to understand the conditions and influences there.
Chapter 8

SELF-ADVOCACY

IN THE FAMILY HOME

1. Introduction

This chapter explores my findings in relation to the families of my respondents with learning difficulties. As explained in the introduction to chapter 7, the overarching themes in these three chapters are the crossing of boundaries and the reality beneath the surface picture. These themes are continued in this chapter.

Chapter 3 suggested two models which are useful. Todd and Shearn (1996a) use a framework of captive and captivated parents to describe parents of adults with learning difficulties still at home. Captive parents would rather not have continuing restrictions but would like to be able to develop their own lives and have their offspring move into independence. They want to be like parents of non disabled adult children. Captivated parents want to continue as parents within the family home, which Todd and Shearn suggest is mainly due to lack of other life opportunities.

Winik et al (1985) used a scheme which Walmsley (1996) adapted:

- supportive families are those which encourage their adult child towards autonomy without over-protection;
• *mutually supportive* families are those where help is proffered on both sides;

• *dependent* families are those in which either the adult child remains protected or a parent is dependent on the child;

• *conflict-ridden* families are those in which tension is not resolved.

I use these frameworks in this chapter to help understand the findings from my research.

Section 2 deals with the conditions and experiences of the families in this research. The difference between surface picture and reality is particularly important. I showed in chapter 3 that the general family literature largely ignores families with disabled members, and that the traditional literature on families with people with learning difficulties has tended to take a pathological approach. Thus the picture is created, in much of the literature, of families with people with learning difficulties set apart from the norm. My findings refute this, but neither are they reminiscent of the glowing accounts of reward and survival also seen in chapter 3. Instead the stories support the many-sided experience found by researchers such as Richardson and Ritchie (1989) and Wertheimer (1989). The lives of the families I researched have been marked by isolation and emptiness. Nevertheless, I found that experiences were shaped by an apparent contradiction between struggle and difference on one side and a perception of normality on the other. This echoes the two interweaving themes found by Richardson and Ritchie (1989). These experiences inevitably affect the impact of self-advocacy at home. Wertheimer (1989) suggested a number of reasons within the family which could impact on the ability of self-advocacy to take place at home. My findings echo her suggestions.
Section 3 moves on to discuss the experiences of my respondents in terms of 'speaking up' at home. Chapter 3 suggested that self-advocacy challenges the expectation of families to care for and control their adult sons and daughters. I therefore look at the findings in terms of this boundary crossing between care and control on the one hand and autonomy on the other.

Control in the family home is a contested area. My findings support those of Wertheimer, who found parents allowing a controlled independence (1989). I found that the people with learning difficulties had significant amounts of control in their daily lives, but this was allowed control; the ultimate control still rested with the parents.

The advisers put forward the idea that people with learning difficulties involved in self-advocacy lead double lives. This concept is used by Simons (1992a) to explain the apparent split between self-advocacy and families. I found double lives but also that people's lives are complex, with interactions of different factors, and that lives do not stay the same.

It must be remembered that achieving change within the family is difficult. Nobody finds change easy, but changing your family is hardest of all: 'It's too personal. Everybody would find that' (adviser). Roles in society are deeply entrenched and very hard to change. It is harder still because of the isolation of individuals within the family. The collective strength and confidence gained from a group could disappear when an individual is on her or his own. People are with their families all the time and rely on them (the statements in chapter 2 from Inclusion International demonstrate this). People value their families and are unlikely to want to upset them. The introduction of new ideas and renegotiation and resolution of difficulties will inevitably not be smooth.
2. Families: difference and normality

This section explores the experiences of families. In a study of parents' feelings about having an adult child with learning difficulties at home, Richardson and Ritchie (1989) found two interweaving themes: the distinct situation facing parents of people with learning difficulties, and the perception that their lives were much the same as all families. My work endorses this apparent paradox. Richardson and Ritchie found the differences to include extra burdens and restrictions, doubts about caring abilities, comparing themselves to others 'worse off', and concern about the long-term future. The similarities included love, anxieties about parenting, changing and renegotiating roles, and teaching independence.

Richardson and Ritchie also found that there were complex responses to caring long-term, both positive and negative. Again, my findings support this. They found effects on parents' lives such as restricted employment, marital strain, effects on other children, and resilience forming a way of life. The families I studied were all different, but there were common themes. I use case studies below to illustrate them. The impact on all the families I interviewed of having a child with learning difficulties was massive. Many faced medical problems and hospital stays throughout early childhood which meant enormous upheaval. Most of the parents experienced total life change. They struggled through years of hard work, sometimes facing prejudice from family and friends. The middle class parents felt they had not been touched by life until they had a child with learning difficulties. The experience of two parents led them to get a job in learning difficulty services, and learning difficulty became the whole of their lives (echoing Wertheimer, 1989).
There were differences between mothers and fathers. Fathers found sharing their feelings difficult. The mothers were all the main carers, and felt that they carried the burden, while fathers felt that they had to be the 'strong one', carrying on working to support their family (similar to the findings of Hornby, 1992). The one exception to this was Mr Shah, who was the sole carer for Daniel after his wife died eleven years previously.

Richardson and Ritchie (1989) found that parents got support, both emotional and practical, informally from family and friends, but less effective support from services. My work endorses the latter, but I also found limited informal support networks. This follows the findings of Grant (1988 and 1993), that networks change over time but the constant is usually the mother, often unsupported for long periods. All the parents I met were unhappy with the way they found out about their child's impairment and with the prognosis, information and help they received. They were left to battle for themselves (this was even the case with Tracey, who was fostered). A number of parents had been satisfied with some services but none exclusively - the main message was isolation and lack of support.

The isolation of the parents was matched by the empty lives of some of the people with learning difficulties. Some went out socialising, though not without restriction, but others went out only to segregated environments or with parents. There were those who barely went out at all. For two, the issue was around not having friends, for others because of control by parents, but only for one did it seem to be his choice not to go out.

Wertheimer (1989) looked at different factors which could influence the outlook of parents. Her general point is that views of the future are influenced by predictions and experiences in
the past. She found that because of inadequate information and little or no help, parents had decided to cope on their own. This led to feelings of bitterness, resentment and scepticism towards services. The impact of continuing physical dependency meant that routines were hard to change. Parents saw themselves as the only ones who could care properly, often doing more than they needed to because it was easier to do so. My work endorses these findings and this is illustrated in the case studies.

Some parents I interviewed seemed to be locked into a negative way of thinking, but most swung between feelings. Most felt guilt about what had happened in the past, and also when they considered their own needs. Feelings about the future were mixed and changing, some wanting their own future, others not seeing a future for themselves (I return to these aspects in chapter 9). There was a sense of loss, tiredness, frustration, anger and sadness. Nevertheless, there was also a strong sense of 'getting on with it'. Most of the parents considered their lives normal, reflecting that perhaps no lives are normal: 'It's not ordinary, but lots of people don't have ordinary lives.' Parents said many positive things - their son or daughter was 'a character', they enjoyed their company, they were proud, they admired their achievements, they had learned from them and become better people themselves. Only two parents struggled to find positives.

I now turn to two case studies to illustrate these points: Mrs Barker, mother of Tracey, and Mr Shah, father of Daniel. These illustrate common themes, but also have different outlooks. They show some issues to do with ethnicity, gender and class differences.
Tracey and Mrs Barker

Tracey was 28, the only one of thirteen children fostered or adopted by the Barkers to still live at home. (Tracey was the only child to live permanently with the family and not be adopted, because social services had not allowed it.) The Barkers lived in a council house. Mrs Barker was the main carer, and in recent years also worked as a carer in a respite service. Mr Barker was a retired skilled worker. He sat in on the first interview but then left it to his wife, Mavis, to continue with the interviews.

Tracey came to the family as a new baby. Mavis was not told there was anything 'wrong' with her:

'...They didn't actually say that her mum was mentally handicapped. They said something about her mum and that she did have fits at times, but due to confidentiality we were never allowed to have a lot of information about parents. That was all sealed under a cloak of confidentiality. So Tracey actually came to us an unknown quantity.'

Tracey started having epileptic seizures and not feeding. For two and a half years the family struggled on with little help or information. When Mavis was told Tracey must have something wrong with her, she refused to believe it, because she doubted her own abilities to cope. It caused a strain on the marriage:

'A child care officer came on the scene, and he said that she had a serious problem. I said no she hadn't, because I was coping and if she had a serious problem I wouldn't be able to cope. But it caused a lot of problems within the marriage because Joe kept saying that I was stupid, because I'd never had a baby I didn't know how to cope with one.'
Tracey eventually had an EEG when she was six, where Mavis met a nurse who had tested Tracey when she was born. What she learned then set in train a life of determination and hard work teaching Tracey skills:

'She called again for Tracey. So I said, "Yes, that's Tracey." And she looked and she said, "I can't believe it, it's a miracle!" I said, "Why?" So then she told me, when Tracey was just a few hours old she'd done an EEG, and the prognosis was vegetable. Her brain was so bad that nothing would ever be done with it. No one had ever told me. So the odds were really stacked against us, and she just is a miracle. So that's how it all started with her. But I just completely refused to give up on her. I fully made up my mind to keep her in the community. When I was told about Tracey, she had severe epilepsy, she wouldn't come to much, her prognosis was poor, and I was very, very suicidal. I felt wretched, I wanted to die and take her with me, an awful feeling. A lot of self-restraint! Because I'm a Christian I just had to keep praying my way through, I felt so bad. Anyway, having got through those terrible two weeks, I decided I'd go hammer and tongs at everything I could possibly think of to give her every opportunity.'

Mavis worked hard for years to teach Tracey skills, with social services trying to persuade her to put her in residential care. The Barkers were satisfied with some services: education was generally good but health services were poor. Mavis had help from some friends and neighbours, though, 'They'll have them when they're tiny but when they get bigger they tend to back off a bit.' She also described being excluded from family gatherings, and verbally attacked in the community for having all those children:

'With fostering, I was bringing things into the family which weren't wanted. Which meant that I began to lose support of family and friends quite badly. Because had I stopped with two white children that were acceptable and in school, that would have been OK. But that wasn't my calling at all. And so therefore I was dealing with children who were completely disadvantaged. Because eventually people had to be told about Tracey, by which time she was nearly three and people could tell something was wrong. And then by that time we'd been asked to have another child, who was black, and that created problems with friends. So it wasn't always easy.'
I was struck by the love and compassion Mavis expressed. Her story has a crusade-quality, fighting to defy the odds. She said she always treated Tracey as normal, expecting the same for her as for the others, but at the same time constantly 'training'. Tracey seemed to me to be a project. Mavis said she still had 'a few things she wanted to work on', such as Tracey's cooking skills, and then she would be 'ready' - as if preparing for her project to be launched. The co-researchers commented that the relationship seemed quite claustrophobic, though they could understand why - there had been such a fight to keep Tracey, there was a poor prognosis, and the family had suffered several losses recently (including the death of one of Tracey's sisters).

Mavis's experiences also led her to get a job in learning difficulty services and set up a mother and toddler group: 'I do that because I was isolated.' Mavis's early isolation was now broken and she had a full life. This was also the case for Tracey, though all her social opportunities were either special clubs or going out with her family. The other children increased the opportunities for Tracey. Tracey copied them, and wanted to be like them. Mavis described herself shutting her eyes when Tracey went off playing and climbing with the others: 'I've died a thousand deaths'.

Despite their evident difficulties, the Barkers considered their life normal. Mavis knew that sounded strange given their circumstances:

'Tracey is absolutely no different from all the other kids.... As far as I'm concerned it's as ordinary as anything, but other people say they don't know how I live the life I do! But to me it's nothing.'

The Barkers were overflowing with positive things to say about Tracey. There were lots of affectionate stories about Tracey when she was younger and now. They were very proud of
all her swimming trophies. Mr Barker described her as a 'card', with a strong sense of humour. Both described her as fun to go out with. Having Tracey had taught Mavis much:

'It's taught me patience for a start, and taught me total acceptance. They all need to be looked at as individuals with particular needs, but not to make excuses for them. Not to be patronising about them, like, "I do this because they give me a lot of love". I don't like "mental handicap", so I'll do all I can and pull all the stops out to help them reach potential.'

'I've had a very, very hard time. In fact to think what she can actually do, it really is a miracle. She wasn't expected to do anything. And that she fantasises and makes things up and does all sorts of weird and wonderful things - I can accept that.'

Mr Shah and Daniel

Daniel was 27 years old and lived with his father in a small council house. His mother had died when he was a young teenager. Daniel had an older brother and sister who were married with children. Mr Shah described the birth of Daniel as 'just one of those things':

'It wasn't no shock or nothing, we just knew it when the baby was born. They told us that he was disabled and that he would be like that all his life. That's all they told us, nothing else. Nothing important. Well, that is important, but that's all... My wife took it harder really than me. Because I accepted it, these things happen.'

Mr Shah played an active part in caring for Daniel. There was considerable impact on family life:

'We couldn't do things as a normal family. We had to break it up in parts. That's how it is. We couldn't go on holiday as a family group because nobody accepted a disabled child in the house or hotel or anything. That was the main problem, because the whole family could not be together.'
Mr Shah described an isolated family, especially as he was never accepted by his wife's white family, and his own family was thousands of miles away. He voiced the feelings of many parents:

'If we'd had proper guidance from somebody who knew the deal with it, then we would have been better, but we never had nothing. We couldn't turn to anybody. It's just trial and error with us.'

Mr Shah's life changed dramatically, not so much with the birth of Daniel as following the death of his wife, when he became the sole carer. He came from a wealthy family in Bahrain and lived a flamboyant lifestyle, building up an international business. Then his wife died and 'life has gone down since' - he never found work again and now lived in relative poverty, reliant on benefits and with 'no life'. Mr Shah's life at the time of the research was blighted by his struggle with Daniel over personal hygiene.

Mr Shah attended a Mencap group for eleven years, but left this when one of the people with learning difficulties attacked a volunteer and the volunteer was disciplined for defending himself. He considered services to be of no help and now felt the bitterness and scepticism found by Wertheimer (1989):

'Got no help at all. Terrible thing was, not even then, when my wife was dying. And all of a sudden they sprung out and there were social workers and they just were there for a couple of days and then I didn't see them again. And that's all really, didn't get no help from anything. I think they're a load of rubbish. They just don't care. As long as they get paid, that's all that matters to them. They couldn't care less, and that is a fact. Sometimes I think the day centre is a waste of time as well, personally. He's not been taught to be independent, nothing.'

Mr Shah said he felt frustrated, angry and sad:

'I feel like screaming sometimes. I feel like walking away, leaving it all, I can't take it any more. He's got no life, I've got no life.'
Daniel was bored at home. This emptiness was partly connected to the control Mr Shah exerted over routines, but Mr Shah also felt it was to do with Daniel's unwillingness to take responsibility for himself. Towards the end of the research Daniel did begin to sort things out for himself and started at a new club. Things did not change for Mr Shah, however:

'I've got no life. None at all while he's here. While he's living here - I'm not complaining - I've got no life at all, completely none. Nilch. Because if I go out with a female friend, if they find out I've got a disabled person, they don't want to know. Which obviously that's true, why should somebody else give their life to looking after somebody else's kid? No.'

Mr Shah said he did not see their lives as normal, but then explained that his life was normal to him:

'I'd say it's entirely different. You can't call it normal life really. Because I'm so used to it I can say it's normal now. I think it's normal to me.'

He struggled to find positive things to say about Daniel, instead emphasising what Daniel could not do, and generalising about all people with learning difficulties:

'As long as he gets something to eat, nobody tells him off, and the television to watch, he's got no problems. Which he hasn't really. I used to go to Mencap charity, I knew every one of them. And they don't seem to have any stress whatsoever. They just couldn't care less. Not really. They live much longer, and that's all really, they live stress-free. They make out that they're upset, and after two minutes they've forgotten all about it. That's one thing I have noticed. They don't seem to get older, it's just one wave-length there all the time.'

Mr Shah swung between thinking Daniel would learn complete self-care eventually to thinking he could not learn anything. He also seemed to have no idea about the agonies Daniel felt over the issue of leaving home (this is discussed in the next chapter). He wanted the best for Daniel but was locked into this negative way of thinking. This was all compounded by his experience of services which taught him that there was no provision that could help them, either at home or for Daniel to move out. Mr Shah saw a bleak future for himself, did not plan, and lived day-to-day:
'Td say there's a big full-stop there, a full full-stop. I can't see nothing really. As you get older, you're just resigned to do one thing and say well, that's it. I can't go any further forward or go backward, it's just stagnant.'

These two case studies highlight the common themes, but also other issues. The increased isolation of parents from outside Britain is illustrated, when their wider families live in other countries and when they face racism here (as discussed by Atkin and Rollings, 1992). Gender differences are particularly noticeable in that the impact of having Daniel did not substantially affect Mr Shah until his wife died (though there clearly were effects on the family as a whole). His role had to change totally to become the sole carer, and he resented this. Mrs Barker, however, was a carer from the start and this became her driving purpose. Class differences are evident too: Mr Shah had descended into a lifestyle of poverty from comparative wealth, which he also resented, while the Barkers were working class and may never have expected anything different. The co-researchers suggest that perhaps with Mr Shah there are cultural factors, both in his expectations of a father's role, and in his approach to disability:

'Probably the way parents were brought up themselves will affect the way they bring up their child. Maybe his attitudes are different because of where he comes from.'

Mrs Barker and Mr Shah have different outlooks. It is probable that the class and gender differences are linked to this. What is clear is that there cannot be a crude 'cause and effect' in families. A materialist approach means that these conditions and experiences are fundamental in understanding the reception within families for self-advocacy, but a dialectical approach requires a recognition of the subjective elements, which means that similar histories do not automatically lead to the same outlooks.
This section has explored the experience and outlooks of the families I studied. Attitudes to the future I come to in chapter 9. The next section turns to the question of control and autonomy within the family.

3. Care, control and autonomy

This section addresses the boundary between control of the person with learning difficulties, one of the expected functions of families, and autonomy, one of the central features of self-advocacy. Chapter 7 showed that there was not a hostility to self-advocacy among the parents I interviewed, and indeed it was seen to have positive impacts in terms of confidence and awareness. Chapter 9 looks at independence and adulthood. This section examines daily control and autonomy within the family setting and the concept of double lives. The section concludes by returning to Todd and Shearn's captive and captivated framework (1996a) and Walmsley's (1996) adaptation of Winik et al's (1985) categories of supportive, mutually supportive, dependent and conflict-ridden families. These are useful for discussing autonomy within the family.

Simons (1992a) found people with learning difficulties who were vociferous in their self-advocacy group but barely had any control at home, and appeared not to be troubled by this. They were, for example, addressed like a child by their parents, were not allowed to go out, and were given instructions for their everyday personal tasks. Wertheimer (1989) also found parents exercising considerable degrees of power, many taking on the role of teacher in the home. They saw themselves as where the buck stopped, but also most recognised that their power could not be total. She found controlled independence, where parents allowed...
autonomy in certain areas but not others. Renegotiation of roles was difficult due to their son
or daughter's perceived status. Some of Wertheimer's parents admitted that their sons and
daughters were more capable than they were allowed to be. They still felt the need to remind
their offspring to do things even if they did not need personal care.

These findings were endorsed in my work. All the respondents with learning difficulties
described control over their basic movements at home, such as getting up and about in the
mornings, deciding when to go to bed, when to bathe etc. In the main they felt that they did
speak up at home, and affirmed that they felt in control (or 'in charge of themselves', or 'their
own boss'). These views were supported by their parents. There were variations however,
including differing perceptions of how much control they felt they had.

As discussed in chapter 3, Flynn and Hirst (1992) found women had less autonomy than men
and people with more severe impairments had less autonomy. Without suggesting that gender
and impairment issues are unimportant, these findings were not echoed uniformly in my data.
There were significant gender issues with Fazila (which are discussed in chapter 9). To help
to understand control at home, I apply the co-researchers' criteria (appendix 3) to three of my
respondents to show varying levels of control and particular issues which arose from the data.

Christine and Vanessa May

Christine was 21 years old, black and working class, living with her mother in an inner city
council house. Her older brother lived with them when he was not working abroad; her
parents were separated. As explained in chapter 7, Christine went through normal schooling.
and it was only on going to college and starting at People First that she was labelled as having learning difficulties. Vanessa, her mother, wanted Christine not to see herself as disabled but to make a life for herself. She saw Christine as her 'little peach', very loving, thoughtful, and a fighter. She knew Christine wanted to be independent, but was a little worried at what she saw as her naïveté, being too trusting and easy-going. She also thought that Christine slipped in and out of taking responsibility.

Christine said yes to involvement in family talks. By this, the co-researchers meant involvement in family discussion and decisions, knowing what is going on, feeling a part of the family, rather than being kept out of decisions or out of family knowledge. Vanessa said she sometimes deliberately did not involve Christine in house decisions, to encourage her on the path of leaving home. Christine thought this was acceptable:

'Because it is her house, she's paying the rent here. And if it was different, like me having my own house, it would be different then, but it's not.'

This is an important point. The co-researchers had thought that a good sign of self-advocacy at home would be the full involvement of the people with learning difficulties in all family decisions. Christine's experience suggests that in fact this would be a sign of the 'mutuality' in Walmsley's framework (1996). Vanessa and Christine saw proper autonomy as Christine being encouraged to develop her own life rather than mutually sharing in Vanessa's.

In regard to control at home, Vanessa said:

'She's got 110% of it! She's got to have her say and I've learned to let her have the last word.'

Vanessa thought that Christine would say she had less control. She was right. Christine said she speaks up at home, but sometimes her mother 'thinks she has to talk for me, she doesn't
let me say my own thing.' Christine resented having some of her life structured by her mother's expectations and said Vanessa still reminded her to do things (echoing Wertheimer, above). Nevertheless she felt in control of her daily life, and accepted that she should be told to do some things around the house:

'This is my mum's house and we each do our little bit, and as long as me and my brother are here we have to do certain things.'

As with family talks, this was not total sharing as the apparent peak of self-advocacy at home but a measured lack of control as part of the push towards independence.

Control over money was a difficult issue for most respondents, but not so for Christine. She had a job and her own bank account. Her mother helped her with the accounts but did not try to control the money. Christine consciously paid towards bills, paying a contribution which Vanessa worked out. Her experience was not typical, as will be seen below.

Another of the co-researchers' criteria was being allowed to go out. Christine went out, though not without restriction. She was expected to tell Vanessa where she was going and with whom, and there was a suggestion that Vanessa could veto some things:

'Because it's getting dark, and there's funny people out there. And like she always wants to know where I'm going because something could happen to you and she wouldn't know where you were or who you're with.'

Christine complained that Vanessa always wanted to meet her friends and vet them; Vanessa said this was true because of Christine's epilepsy. She wanted to be sure she was with people who would understand and help. Here there are the fears of risk pointed to by advisers, and echoing Wertheimer (1989).
Christine raised an interesting point regarding sharing and talking. She thought Vanessa talked more to her brother because he was older. She showed a desire to be allowed into her mother's concerns in an adult fashion:

'I think sometimes she doesn't always tell me the truth. She'll only tell me half of it and she'll say, "I'm all right, nothing to worry about..." I don't think she really thinks I'm grown up enough yet, that I really fully understand.'

Christine also thought that as you grow up you tell your parents less: 'As you're growing up you tend not to tell them everything you're doing.' There are evidently different sorts of talking, the child telling the parent everything and two adults sharing. Similarly to 'family talks' and house rules, a lot of talking and sharing is not necessarily a sign of self-advocacy, it is the kind of talking and sharing that counts. What seemed to be happening here was the renegotiation that takes place in all families as adolescents get older (Youniss and Smollar, 1985; Brannen et al, 1994).

**Jason and Mrs Cooper**

Mrs Cooper said speaking up was good but Jason could not do it:

'If there's anything he's got to say, he does tell you his mind at times, but you can't understand. He can't make decisions for himself.'

In answer to the question did he speak up at home, Jason replied, 'Not me, I can't. My mum do it.' He had some control over the basics each day:

'I get ready for work, I get up myself. I can wash under my arms. My mum washes my hair. My mum does shaving good for me. Cereal for breakfast, I get it. My mum tells me to go to work because I don't want to be late. Mum gets dinner but I choose. I go to bed myself.'
Mrs Cooper encouraged him to be autonomous in the home, but was pessimistic as to his abilities to be so:

'The tries to be independent, goes up the road, goes shopping, if I give him a list he'll go. He should be more independent, but it's his brain... He makes himself something to eat, cup of tea, he can't get into a meal. I shown him at times, how to cook, so he can do jacket potatoes. I pray he'll go from strength to strength. I show him, tell him what he should do.'

Jason did not go out, apart from to a special club. This seemed not to be connected to lack of control. Mrs Cooper wanted him to:

'The won't go out. I say find yourself a girlfriend, but he won't go out, he doesn't like it. Especially when he hears all the trouble outside, he gets scared.'

There was no evidence that he aspired to a social life. Mrs Cooper said he was like his father in this respect - he stayed at home and enjoyed having the house to himself. My co-researchers suggest that his choosing to stay in may be a consequence of isolation:

'Maybe he feels he can't go out and meet other people because he's stayed at home so long.'

Tracey and Mavis Barker

Tracey felt in charge of herself, getting herself up and out in the morning and sorting herself out at night, and spending her time in the house as she wished. But she felt that she did not yet make all her own choices, for example, she had to ask her mother for money.

Tracey's control over finance is an interesting point. She had very little control compared to Christine and Katya, who both worked, but more than the other respondents. Her parents kept Tracey's benefit money and handed over spends. Tracey had no knowledge of the amount of her income and was uncertain whether the money she was spending was hers or
her mother's. Mavis gave her around £20 each week. She said Tracey did not have to account for everything, but if she was spending unwisely then Mavis would intervene. For five years Mavis gave Tracey an additional £5 on a Saturday to budget, to get some food for herself and her dog, but she spent it on sweets, so Mavis stopped it. Mavis presented these arrangements as Tracey having a lot of control, but the money was clearly well under Mavis's control, and Tracey felt this. Nevertheless, Tracey did have more financial freedom than many of the other respondents, who were daily given the precise amounts that their parents thought they would need.

Housework is another interesting point in Tracey's experience. The co-researchers saw this as an important sign of people making a contribution to the household on an equal basis, being valued, and being able to help. For Tracey, housework was all part of her 'training'. Mavis explained:

'She has to keep her own bedroom clean.... She is responsible for changing her clothes regularly and putting them in the wash.... Saturday she is expected to get a couple of bits and pieces.... I see all this as things she has to do for herself. It doesn't often go wrong, but she forgets and we have to give reminders.'

As with the others, Tracey only did the safer tasks rather than those seen as more risky, such as ironing. Rather than a respected, equal contribution, these were things Mavis made her do so that she would learn skills. There are echoes here of Baistow’s point about the dilemma of empowerment (1995): is it possible to for Mavis to empower Tracey or does this negate the purpose of empowerment? Barnes (1997) argues that parents can empower their offspring, and this would seem to be the point of the apparently accepted need for parents to know about self-advocacy. Mavis interpreted her own efforts as empowerment and helping self-advocacy, but I also had a sense that Mavis was firmly in control, perfecting her project.

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These case studies show a number of interesting points. Firstly, in families in which there was a push towards gaining autonomy, there was less sharing and joint decision-making, the suggestion being that total sharing would be more in line with a long-term mutual relationship rather than one in which the person with learning difficulties was expected to gain autonomy and perhaps move on.

Secondly, although there were similar general experiences - all the respondents had basic daily control - the perceptions of control and outlooks of the families differed. With Christine there was a sense of direction. Both she and her mother were aiming not just for autonomy in the family but independence from the family. She had a job, controlled her own money, and although still subject to her mother's control in some respects, there was a sense of her being on a path potentially of her own making. With Jason, there was a much stronger sense of Mrs Cooper being in control and Jason being allowed out on a rein. Both Jason and Mrs Cooper perceived him as having little control. With Tracey there was a path, a sense of direction, but this was under Mavis's control, and Tracey would not be ready until Mavis said so. She was being trained, and her autonomy was controlled.

Thirdly, there were some areas in which parents particularly seemed to want to maintain control. Money was an area where hardly any of the respondents had control. There was a clear distinction between budgeting with their own income, and controlling that which was allocated to them by someone else and which they did not even perceive as theirs. The co-researchers saw this issue as particularly important, pointing out that parents seem to see finance as all-or-nothing: 'You may need help to budget but you can still be in control.'
Safety was another issue which meant limits were drawn - even for Christine. Self-advocacy was acceptable if it was regarding day-to-day matters within the home, but harder even for the most supportive parents on other issues. Much of the autonomy the respondents experienced would seem to be the controlled independence of Wertheimer (1989). When it came to steps which were on the edge of the safety mark, self-advocacy became a lot harder. This point will be explored in the next chapter.

Before returning to the family frameworks, I wish to turn to the idea put forward by several of the advisers I interviewed, that many people with learning difficulties involved in self-advocacy lead double lives. This was a concept found by Simons (1992a), who suggested that many people with learning difficulties were like two different people - one in their self-advocacy group and another at home. I want to consider this in the light of my findings.

The advisers were eloquent on the subject of double lives. Janet, adviser to 'B' group, said:

'Particularly with the people in that group, I think they know what they can say at the day centre, and when they're at home they know what they can say in the home environment. I think they know what rocks the boat at home and what causes problems at home. So I think they kind of switch roles, and they're very good at it.'

Simon, adviser to 'J' group, concurred, but emphasised also that there was a mixed picture:

'When they're with us they can be a very dominant figure, a leading figure, they take a leadership role with the group, very forward, quite persuasive to some people and able to motivate others. And then you take them home and their parents perhaps treat them as if they're only five or six years old and totally undo all that work, and undermine that person's confidence and so on. What is picked up is that parents do actually notice that somebody is gaining loads of confidence, say that there's things they never knew they understood, and there's a few surprises from time to time. But unfortunately, I think that their ability to continue down the sort of road that we do is often a problem. Not in all cases - there's some wonderful parents out there that will do anything in order to let their son or daughter live an independent life, and help them with mistakes.'
The advisers believed this must lead to frustration. Janet said:

'Because they've been told they've got all this power and they can change things and blah, blah, blah, and they can have control over their environment, and they go home and it's not happening. I think it can make people very frustrated and very angry.'

However, the picture is not so clear cut as people simply leading double lives. Simon himself indicates that it is a long process and that change can be seen. (It is ironic that advisers talk about double lives in regard to home life, when chapter 7 has shown that advisers may not allow people with learning difficulties much control within the self-advocacy setting either.) I use the example of Esther to illustrate the complexities.

**Esther Cohen**

Esther Cohen was 61 years old and at the start of the research lived with her elderly mother. When I first met Esther, she lived what might be thought of as a classic double life. At her day centre, where she ran 'B' user group, some of the other users affectionately nick-named her 'God', a title she appeared to relish. She became chair of 'A' People First and was involved in a number of user involvement opportunities. Esther was even described by her day centre manager, Susan, as having 'an inflated sense of power'. But at home, Susan said, 'Esther was never empowered, despite having a high profile and being very articulate elsewhere.' Janet, the former 'B' group adviser, said she thought Esther's mother had a lot of control over her.

Certainly Esther felt that her mother tried to run her life, and she wanted to leave home.

Esther described herself as fairly self-sufficient while she lived with her mother, getting herself up and out in the mornings and partially running the home:
'I stay at home and do the housework now, and mum goes out across the road, and she comes back. I told her to keep out of the flat while I do the flat out. I do all the way through, and she can't tell me what to do, I know what I'm doing myself. I understand, I clear up, wash up, and she sits down and has a rest and does the bingo. I want to go in the kitchen, she doesn't like that, she goes in and out. So I don't go in the kitchen.'

Esther's overriding thought was, 'It's my life, not hers.' She said she had been living with her mother too long. Esther said she was not involved in family talks: 'How can I be involved when people tell me what to do?'

'She keeps telling me off a lot. I don't like it. Living there is no good to me or her.'

At 81, Mrs Cohen seemed to be a lonely and frightened woman. Esther had been removed when she was two years old, and Mrs Cohen still felt guilt and bewilderment about the early days:

'They took her away, didn't they. She was two when they took her away. Because I had three other children, I couldn't cope. She had one convulsive fit, and that was that. She had one fit that paralysed her down the right side, and she didn't grow anymore... I had three other children to console me so it wasn't so bad. They were all right, those three. But she only had the one convulsive fit, and that took her back... I said to the doctor then, "You should have let her go".'

I asked if she still felt that now. 'No. Now I'm lost without her.' Esther had returned to Mrs Cohen when she (Esther) was in her early 40s:

'The family didn't like it, they thought I was doing wrong, but when they saw her, what she was doing, and how I brought her up, they thought it was marvellous, I done wonders.'

Having Esther back changed Mrs Cohen's life and gave her a chance to start again with a whole new focus. She taught Esther embroidery, crochet and knitting, and how to do housework. She attempted to teach her cooking, and tried to teach her to read and write. She did not manage this, but Esther did learn to type.
Mrs Cohen did not know that Esther was in a user group at the centre, but she did know that the centre was 'putting ideas in her head' about leaving home:

'It seems that people are talking her into move out. She knows if she moves out, that's the last she'll see of me. Naturally I don't [want her to leave]. I'm lost without her. I don't know. I wish they wouldn't talk her in, that's all. I can teach her things, I don't mind teaching her to cook and things like that. But they're trying to talk her into leaving her home.'

It seemed that in her wish to keep Esther, Mrs Cohen felt it necessary to point out all the things Esther could not do. Thus, although she clearly felt immensely for Esther, she was very negative about her. The co-researchers wondered if Mrs Cohen could get some care help herself, so that Esther could move on. They thought that if Mrs Cohen did not have to depend on Esther, their relationship might improve.

During the research Mrs Cohen became ill and Esther was moved into a hostel while her mother was in hospital. Esther grabbed this opportunity, declaring, 'I'm not going back, she can't tell me what to do no more'. It took a year of being pushed from pillar to post for Esther to finally get her own adapted flat as part of a community support scheme. When she got this flat she was tremendously proud, explaining how it meant she could have friends round and go to bed as late as she wanted.

Esther had mixed feelings about the support she got from her mother during the moving process: 'She's been great with what I'm doing. She wants me to have my own life'. However, 'I don't want to go back to her, she's the one who can't understand.' Esther felt for her mother left behind:

'I think she will be very tired. I'm really very sad for her in that flat. I want her out of there because it's no joke for her.'
She was pleased when her mother went into sheltered housing near one of her other daughters. Esther reported that Mrs Cohen had accepted that Esther had her own place and she was starting to enjoy her own new life. Mrs Cohen died shortly after the research ended and Esther was very upset, especially that her mother had never seen her in her own flat.

Esther’s story demonstrates a number of points. We see here Walmsley’s category of dependent parent (1996) and the caring role carried out by people with learning difficulties. What is also clear is the bond between Esther and Mrs Cohen, which, as Wertheimer found, was particularly strong after years of care (1989). In chapter 7, I showed that, for Kevin, the double life was a strategy for dealing with conflict over self-advocacy, a compromise position to make life run as conflict-free as he could manage. For Esther, however, the double life was far from this - it was a cause of constant irritation and a spur to grasp the opportunity of her mother’s illness to move out. There was frustration and conflict for Esther directly arising from her involvement in self-advocacy. But although she may have felt for a period of time that ‘nothing changes’, her situation did change. Her experience demonstrates that resolution of conflict is possible and even double lives do move on.

I return to Todd and Shearn’s framework (1996a) and apply it to my respondents. As a reminder, the captive parents are those who would like to stop being parents; the captivated are those who want to stay as parents.

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<th>captive parents</th>
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<tr>
<td>Eva Klein</td>
<td>Mrs Cohen</td>
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<tr>
<td>Mr and Mrs Papandreos</td>
<td>Mrs Cooper</td>
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<tr>
<td>Mr and Mrs Banks</td>
<td>Mr and Mrs Waluk</td>
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<tr>
<td>Vanessa May</td>
<td>Mr Shah</td>
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<tr>
<td>Mavis and Mr Barker</td>
<td>Mr and Mrs Begum</td>
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There are problems with this framework. Firstly, the categories are mutually exclusive while real experience is more complicated. For this reason, I have placed Mr Shah, Mrs Cooper and the Barkers in their categories with some reluctance. Mr Shah and Mrs Cooper had elements of 'captive' parents about them: Mr Shah was resentful of his role and the impact on his life; Mrs Cooper was tired and got through life with a sense of drudgery. They both said that they would like their sons to move on. Nevertheless (as will be seen in chapter 9) they both also put up many barriers to their sons' independence, as if they were afraid of change. They both certainly lacked anything that would fill the gap. In the case of Mavis and Mr Barker, I have placed them in the captive category because they were aiming for Tracey to leave home and had ideas for their own life; on the other hand, developing Tracey had been a life project for Mavis and one she was unlikely to relinquish before she had determined Tracey was ready.

Secondly, also problematic is Todd and Shearn's idea that parents are captivated through lack of opportunities. This is supported in the cases of Mrs Cohen, Mr Shah and Mrs Cooper. However, there is a sense in which the Waluks and Begums are not so much in want of other opportunities as positively choosing this one. I will introduce the reader to Fazila Begum's situation in the next chapter, where this idea of choosing to remain together will be explored.

Thirdly, the term 'captive' is negative: it suggests that parents who want their own lives are trapped. This may be the case with some. Eva, for example, felt frustrated that Katya was not moving on smoothly and perhaps would describe herself as captive. But the others, though they had worries, were taking steps to allow themselves and their offspring to move on.

Fourthly, missing from this framework is the notion of interdependence (Walmsley, 1993b). A number of my respondents with learning difficulties were not just receivers of care. Fazila's
parents and sister were physically dependent on her. Mrs Cohen was emotionally and to a lesser extent practically dependent on Esther, and Esther wanted to get away. Although I am sure Mr Shah would deny it, Daniel wanted to leave but felt a responsibility for his father's emotional well-being (as will be seen in chapter 9). It may therefore be useful in these instances to apply the captive and captivated categories to the people with learning difficulties themselves.

captive son/daughter

Daniel Shah
Esther Cohen

captivated son/daughter

Fazila Begum
Kevin Wahik

The categories used by Winik et al (1985) and adapted by Walmsley (1996) are useful to develop this analysis further.

supportive parents

Tracey and Mr and Mrs Barker
Michael and Mr and Mrs Banks
Anita and Mr and Mrs Papandreos
Christine and Vanessa May

mutually supportive families

Kevin and Mr and Mrs Wahik
Fazila and Mr and Mrs Begum

dependent adult child

Jason Cooper

dependent parent

Mrs Cohen

This scheme allows for conflict and a blurring of experience, rather than the mutually-exclusive nature of the other categories above. The conflict-ridden families are those in which
there is as yet no resolution. Nevertheless, people still overlap into different categories - for example, I have placed Jason in the dependent (adult) child category, but this does not mean that Mrs Cooper was unsupportive. The Begums are in the mutually supportive category, but chapter 9 will show that this is not without complications. Importantly, nothing is static. People and their circumstances change. Mrs Cohen features here in the dependent parent category, but this does not indicate that Esther was there to stay - she moved on and her mother did manage to develop an optimistic view of her own new life. There is nothing to say that conflicts cannot be worked through nor that family crises will not act as a catalyst and change the relationship. Apparently stable families now could face difficulties in the future when the circumstances change. What will happen, for example, in Michael's family when the challenge comes?

This section has raised points regarding independence and preparation for the future. Chapter 9 takes up this discussion.

6. Conclusion

This chapter has discussed the experiences and outlooks of families and the reality of self-advocacy at home for my respondents. My findings have refuted the traditional pathological literature on families with people with learning difficulties and have supported the rounded studies such as Richardson and Ritchie (1989). I have found families characterised by the apparent paradox of difference and normality. My research has supported the findings of Wertheimer (1989) regarding factors which influence parents' outlooks. My work also shows
that a materialist approach has to be dialectical to fully represent the life experience and outlooks of families.

The chapter has discussed the boundary between care and control and autonomy, supporting Wertheimer's suggestion that the independence allowed within the home is controlled. The concept of double lives suggested by Simons (1992a) and used by advisers has been shown to be partly founded, but that the reality of experience is more complex and changing.

I have used different frameworks from family theory to help illuminate these experiences. I have used the captive and captivated framework, but I have shown it to have limitations. More useful has been Walmsley's (1996) adaptation of Winik et al's (1985) categories. It is within the supportive families that self-advocacy seems to take place most smoothly, though even here there is still the question of boundaries around people's autonomy. The issue here would seem to go back to the question of care and control and societal expectations of families. The normal family control ends with adulthood and independence; with people with learning difficulties it goes on. This raises questions about adulthood and the label learning difficulties.

The next chapter will look at how the issue of identity interacts with the question of independence and self-advocacy in the family.
Chapter 9
INDEPENDENCE AND IDENTITY

1. Introduction

The discussion in previous chapters has pointed to the importance of independence and adulthood within the experience of self-advocacy and families. Chapter 8 explored control within the family, which inevitably raised the question of developing independence. This chapter examines the related concepts of autonomy, independence and adulthood in the context of self-advocacy.

The two themes of the reality beneath the surface and crossing boundaries continue through this chapter. My findings refute certain stereotypes of families in regard to planning for the future. One stereotype, often held by service workers, is that parents hold back their sons and daughters with learning difficulties, while they want to move on (as suggested by Sutcliffe and Simons, 1993); another, found in the literature (e.g. Richardson and Ritchie, 1989), is that the people with learning difficulties are relatively passive in the transition process. This chapter explores the reality behind these assumptions. The chapter also looks at two boundaries: between childhood and adulthood; and between adulthood and learning difficulty.
Chapters 2 and 3 discussed the importance of the distinction between independence and autonomy. Oliver (1990) and French (1993b) take up this issue in regard to personal assistance and independent living. They argue that what is required is not self-sufficiency, but control over help - that is, autonomy rather than independence from help. This distinction is important when considering my findings. My respondents all lived with their families, but most already considered themselves independent, meaning that they had some autonomy.

There follows from this a second distinction between autonomy within the home and independence from it. This chapter will show the importance of this with Katya and Eva Klein - both wanted Katya to have 'independence' but to Eva this meant she hoped Katya would leave home at some point in the not too distant future; to Katya it meant she wanted to maintain her independence within the family home. In this chapter I use 'autonomy' to indicate control, and 'independence' to mean leaving home.

I argued in chapter 2 that self-advocacy aims for autonomy, and that this is intimately linked to a claim to adulthood. Independence (in terms of leaving home) and autonomy are both markers of adulthood (e.g. Clare, 1990). This chapter explores these interlinked concepts, using the markers of adulthood laid out in chapter 3: leaving home, getting work, forming partnerships and parenthood. I find that while my respondents aspire to these markers, they have in the main not achieved them.

Jenkins (1989) makes the point that even in the absence of such markers, young people still attain adult status, principally because it is a social role which parents and adolescents want and expect to achieve. He argues that people with learning difficulties are denied adult status,
because of the social identity of learning difficulty in medical, legal and popular models. I therefore examine the views and expectations of my respondents with learning difficulties and their parents regarding adulthood. The parents described people with learning difficulties as being in a 'suspended phase' - not children, but not quite achieving adulthood either. The people with learning difficulties either saw themselves as adults or as in transition.

In chapter 3 I discussed the identity of people with learning difficulties and argued that in rejecting labelling, many people with learning difficulties are redefining their own identity. I discuss this in the light of my findings and find at least some of my respondents reject the social identity of learning difficulty in favour of adulthood. (It is because these two constructs are thus connected that this chapter is entitled identity rather than just adulthood.)

Chapter 8 used frameworks for understanding autonomy within the family. The general family literature has useful models for moves towards independence and adulthood. Brannen et al (1994) use the concepts of individuation and connectedness. Individuation is applied to families that value independence and prepare for it; connectedness to families that want to stay together and place less value on independence. Brannen et al (1994) also use two models of transition to adulthood. One is where adulthood is achieved, when the young person is freed from parental interference and forges her or his own identity and lifestyle, and ascribed, when parents confer responsibilities and adult status. Brannen et al use the division mainly in regard to different ethnic/cultural groups, using the ideas of connectedness and ascribed status to describe families of non-UK origin. I find both these frameworks are useful for understanding the experience of my respondents with learning difficulties. The cultural issue is particularly important, and I explore this aspect with the experience of Fazila Begum.
My work shows that individuals and families have different hopes and expectations regarding adulthood, in which the distinction between autonomy and independence is very important. I ask the question, has self-advocacy, in championing autonomy, fallen into the trap of actually championing independence, thus not representing the wishes of those people and families who hold other values more highly?

The chapter is structured as follows. Section 2 introduces key issues and discusses my general findings in relation to existing literature and theory. I use four case studies as the centrepiece of this chapter, in section 3. It is not possible to separate out questions of independence, autonomy and adulthood, and so I offer stories which incorporate a number of issues. Sections 4 and 5 then analyse the points raised in the stories: section 4 around autonomy, independence and renegotiating roles; section 5 around adulthood and learning difficulty.

2. Autonomy, independence and adulthood - the issues

I suggested in chapter 2 that autonomy, independence and adulthood are integral to self-advocacy. This is reinforced in my work, where my respondents defined these terms similarly. For example, Michael said of self-advocacy, 'All I know is it's an adult thing.' Tracey defined adulthood as 'doing things independently'. Parents and advisers made the same links. These terms require some analysis themselves, before I move on to explore the experience of them.

Chapter 2 showed self-advocacy to claim autonomy in that it aims for rights, choices and control. Autonomy is an elastic term which does not prescribe particular settings. Autonomy is not a term used by any of the people with learning difficulties I interviewed. They use the
term 'independence' to mean the same thing. Tracey, Katya, Michael and Fazila all saw independence as achievable within the home. They gave examples, which included having responsibility, 'going on the bus on my own', shopping, controlling money, having a door key, looking after themselves, and being on their own in the house. Anita, Esther and Christine saw independence as requiring leaving home. The people with learning difficulties here give independence a broader meaning than that in common parlance, where it is used to mean free from help, or self-sufficiency, especially in the context of personal care, such as washing and cooking. Many of the parents I interviewed interpreted independence as leaving home.

As I explained in the introduction, Oliver (1990) and French (1993b) point to the importance of the distinction between independence and autonomy. To define independence as freedom from any help is in itself disabling. Some people would not be able to get out of bed in the morning without help and many people with learning difficulties are unable to perform practical care tasks without help. In fact, interdependence is a feature of human society (Dalley, 1996). The important point, then, is not to be independent from help, but to have control over that help, i.e. to have autonomy. The self-advocacy literature, in championing 'independence', much of the time would appear to mean autonomy, and I suggest that it is perhaps a weakness of the literature that this distinction is not made sufficiently clear.

Autonomy and leaving home were both of significance to my respondents, and intimately linked to adulthood. Markers of adulthood were discussed in chapter 3. My respondents' experience of autonomy in the family home was discussed in chapter 7. This chapter particularly looks at the other markers: leaving home, work, partnerships and parenthood.
Briefly I present the experience of all my respondents to give a general picture. The case studies in section 3 explore these in detail.

Leaving home

both parent and person with learning difficulties want the person to leave home

Christine  Anita  Tracey  Michael

both want to stay together  conflict

Fazila  Kevin  Katya  Daniel  Esther  Jason

Work

got jobs  got work experience  aspire to work

Christine  Katya  Michael  Jason  Anita  Fazila

no aspirations  had work in past

Tracey  Daniel  ?Kevin  Esther

Partnerships

got one already  aspire  do not aspire

Tracey  Daniel  Jason  Christine  Esther  Katya  ?Kevin

Michael  Fazila  Anita

Parenthood

None were parents or really expected to be.

These markers were recognised by the respondents with learning difficulties as signifiers of adulthood, and as such many aspired to them. But it is also clear that they were largely not
yet attained. Wertheimer (1989) found that some markers were more acceptable to parents (e.g. jobs) than others (e.g. sexuality), and this chapter explores this. Leaving home was the marker which had most significance for my respondents and their families.

Wertheimer (1989) warned against the stereotype of parents holding on and people with learning difficulties wanting to leave. This stereotype is implicit in much of what my advisers had to say. Wertheimer found that leaving home was hard for parents to contemplate, but that their adult children could also find separation difficult. She also found parents who wanted their children to be independent. She comments that all parents find these issues difficult, but that with parents of people with learning difficulties the timescale is often longer and the bonds closer the longer the person stays at home. My research reinforces these findings.

I find a second stereotype in some of the (limited) literature on leaving home. This is the assumption that the issue is all down to the parents: the views of parents are the focus, and they are taken as the only active players. The people with learning difficulties are assumed not to initiate developments. My findings refute this. This is not to suggest that there is not useful work on parents' views that can inform my findings.

Richardson and Ritchie's important work on 'letting go' (1986 and 1989) found three positions of parents - those seeking a move (due to health reasons or emergencies, long-term planning, or a feeling that the 'time has come'), those who did not want their son or daughter ever to leave, and those who were ambivalent. I similarly found these positions, and that parents could express more than one view.
Richardson and Ritchie (1989) found various reasons why parents made the decision to keep their offspring at home. Many parents felt it was their responsibility and that their home was the 'proper place', often ideas which were reinforced by services and society - the parents who kept their children at home were the 'good' ones (though there is an ambivalence here, with such families also often characterised as 'over-protective'). They found some parents who planned for their sons and daughters to leave, but many who got into a habit of living day-to-day, growing in mutual dependency and thinking nothing would change. It was not until they got older that they started to realise their own vulnerability. I found parents with a day-to-day approach, though some were conscious that this would have to change.

For Richardson and Ritchie's parents, the future seemed bleak. This was partly a question of who would care for their son or daughter - there were grave concerns about where they could go and the adequacy of services - but also a question of who would care about them. This was reflected in the views of some of my parents. What stands out in my work, however, is the significant number of parents who did not live day-to-day but did plan: for independence for their sons and daughters, or for them to stay in the family. Even in the conflict/ambiguity category, with Katya and Eva there was planning. Their conflict arose from each planning different things.

Card (1983) found that one of the key reasons many parents wanted to keep their sons and daughters at home was because they did not see their child as an adult without the normal experience of adolescence and the child pushing to make changes. In these instances it is the parents who have to take the initiative. This was the case with some of my parents. Wertheimer (1989) found that it is hard for parents to see their sons and daughters as adults.
in the absence of other markers such as jobs and relationships. As discussed in chapter 3, achieving these markers is not a straightforward issue for any young person going through the transition to adulthood. Nevertheless, Jenkins (1989) found that long-term unemployment, for example, does not prevent young people from becoming adults. This is partly because of other aspects such as legal thresholds and benefits, but mainly because parents and children want it:

'Adulthood in Britain is a robust, if imprecise, identity, of which people can only be deprived by circumstances that undermine its central portfolio of rights and obligations' (1989, p.102)

One issue my case studies explore is, in the absence of markers for my respondents, do they see themselves as adults?

This section has briefly analysed meanings of autonomy, independence and adulthood, and pointed to some of the important issues. The next section presents the stories of four of my respondents, which illustrate the range of positions and issues raised in this section. Sections 4 and 5 will then develop the analysis further.

3. The stories

The reader should refer to the case studies in chapter 8 or the vignettes in chapter 6 for background to these stories. The exception is Fazila, who has not been discussed in the findings chapters till now, and so her story here has more background detail.
Katya and Eva Klein

In this family, it was the mother who wanted her daughter to leave, and Katya who wanted to hold on. Their story demonstrates different aspirations to autonomy in the home and independence from it. What is also shown is how someone can be perceived as an adult through behaviour and appearance.

Katya had a high degree of autonomy within the home. She often coped on her own for two weeks at a time when Eva was away, but when Eva was at home Katya did less, seeing housework as her mother's responsibility. This frustrated Eva, because Katya would not take responsibility for herself. She said when Katya did tasks she did not look at whether she had done the job properly and then Eva had to deal with the consequences. Eva had taken a conscious step to lessen her control over Katya and allow her autonomy. She said all parents try to control and protect, but it is not possible to do so totally: 'I don't always know what she's doing. And I had to learn, as every mother had to do, to let go.'

However, there was argument about the future. Eva wanted Katya to move on and was determined to have her own life:

'In recent years I've been telling Katya she should be preparing herself for moving out, and this is my house, and that she should be thinking that if she wants something different she needs to think about moving out. So there have been times when I've not involved her deliberately. Because it's nice and cosy at home, she needs to move on sooner or later. And there are times when actually she is demanding things which change my life, and I'm getting resentful of that.'

She said the next step was for Katya to try out her aunt's flat, now empty because her aunt had died. Eva had not moved decisively on this because she thought it would become clear when 'the time was right'. However, during the research this issue became an increasing
source of tension. Katya did not want to use the flat. In fact, for Katya, being allowed autonomy in the home was a reason to stay. She said she wanted independence, but meant this as autonomy within the home. Her younger brother having left did not make Katya think that she could:

'He's just making a life of his own. He's able more than I am, and he doesn't need the help I might need, so let him get on with it!"

Eva felt frustration at what she saw as Katya's lack of responsibility and lack of making plans. Eva did not want to make plans for Katya, but found it hard when Katya did not. Eva saw it as a contradiction, even a failing, of self-advocacy. She had hoped self-advocacy would help Katya to leave home.

Eva would also like Katya to have a partner, but Katya was not interested. She found it an embarrassing subject - she giggled and deflected questions. She said she did not think about it. Eva had more mixed feelings on the idea of Katya having children, because in her social work she had to deal with the 'reality' of inadequate support and potentially 'tragic' lives for the children.

Katya's job as a self-advocacy development worker was very important to her. She had always been determined not to go to day centres because she knew someone who did and it 'put him back'. Eva said:

'Katya, at this moment in time, is happier than she's been for a long time because the job is giving her a lot of job satisfaction.'
Katya saw herself as an adult and said she was treated like an adult, though sometimes she thought Eva spoke for her. Eva was the only parent who firmly saw her daughter as an adult, though this was not without struggle. She said Katya had had a long adolescence; but she was not an adolescent any more - 'you can see the lines'. She had been forced to see Katya as an adult because of her behaviour:

"When she was young I used to watch her and how she played and now I don't. I quite deliberately know that she can handle herself and I let her go. I don't know all her thoughts anymore. When she was a child she would chat and talk and now she doesn't. She does come out with thoughts and ideas which obviously are adult. She isn't on my mind 24 hours a day. It's this letting go which to me indicates that she's not a child, she's an adult... Sometimes as a parent you feel quite guilty, because she can be around here even and she's not on my mind."

Daniel and Mr Shah

This story is reminiscent of many of the experiences Richardson and Ritchie found (1989). It is not simply a case of Daniel wanting to leave and Mr Shah holding on. Feelings are complicated on both sides, and the situation is wracked with tension and worries. Services - or lack of provision - bear a responsibility here.

Communication between Daniel and his father seemed to be poor. Many times over he said he could not talk to his father about the future and his wish to leave home. Mr Shah said they had talked but Daniel 'doesn't take it in'. He said Daniel did not understand that he needed to be clean first, and that there was nowhere to go. He also said Daniel was not really capable of long-term plans. Mr Shah wanted Daniel to speak up, but then put him down because he argued about the 'wrong things'. He said Daniel had his own mind, but then described him as a programmed machine; he could not make big decisions and was unable to learn.
Nevertheless, Mr Shah also said, 'Every right that I've got, he's got the same right.' There was a sense in which he recognised that Daniel was thinking about something:

'He won't say what he thinks, he just says, 'Don't know'. I say, 'You do know, you just won't say it'.'

Mr Shah clearly had affection for Daniel and had tried to teach him to be independent, but he believed Daniel had no realistic thoughts of the future. In fact, Daniel was torn about the future. He wanted to leave home and have his own life, like his brother and sister, but also felt a responsibility to stay with his father, who would otherwise be left with no-one:

'My brothers and sisters have moved out, I been living with him the longest. And I want to move out.'

'I do want to tell my dad that I want to move out, but I don't know how. Because he's got no one, he's on his own. And if I go he'll be all on his own. I don't want that, but -.'

Mr Shah did not know about these thoughts, and made no plans:

'As far as I know his future is bleak. He'll end up in a home if I die. Funny enough I just live day-to-day, I don't make any plans. I have never ever made plans, if I make plans they always seem to go wrong... He can't do nothing. He'll end up in a home.'

One of the problems he saw was lack of provision: 'Well, social services can't do that support anyway. I've seen it.' Nevertheless, he felt both their lives were very restricted, and said he would like Daniel to be able to leave home at some stage in the future.

Daniel had an on-off relationship with a woman at his day centre, but his father did not seem to take this seriously. Daniel would like to get married and had vague hopes of having children one day. Mr Shah said a long-term relationship was possible but unlikely:

'I didn't stop any of my other children so why should I stop him?... If he falls in love with somebody or wants to live with somebody, yeah, I wouldn't stop him. But at the moment he falls with everybody in love!'
Daniel wanted to talk to his father about developing his relationship with his girlfriend but felt he could not. He said he would like to her see her 'especially in the evenings', suggesting sex, but then became embarrassed and apologised to me for mentioning the subject.

Regarding work, Daniel said he wanted to stay at the day centre rather than get a job. Mr Shah said, 'Oh, no, no, no. Day centre. No, I can't see him getting a job, there's no possibility.' How much Daniel's position was truly what he wanted and how much was to fit in with his father was not possible to tell.

Daniel saw himself as an adult. He said he was treated like an adult at home, because he could do things for himself and was able to go out on the bus. Mr Shah said Daniel was like a three year old. At other times, he referred to Daniel as an adult 'he is old enough to know his own mind' - but then qualified this with a rider - 'at least in years'. He said that Daniel took no responsibility for himself, and that he talked better with the grandchildren:

'He's talking with them, screaming like babies do, "No, this is mine, you can't have this!" like that. Then you know how far his mind is developed, that's the only way you can tell.'

The co-researchers thought that Mr Shah was ignoring the evidence of Daniel's adulthood because he wanted to cling on to him as a child, for his own security, afraid of change. They also wondered if Daniel still needed to accept he was an adult and to realise he had to take responsibility, then maybe Mr Shah would be forced to see him that way.
Fazila and the Begums

Fazila's story is particularly interesting. It demonstrates a different value system to that assumed by much of the literature on growing up and leaving home. There are clear cultural and gender issues here. Fazila and her family wished for her to stay in the family, though there were still contradictions and conflicts within this.

Fazila was in her late 20s, an Indian woman and member of 'F' user group. She lived with her parents, two older brothers and a younger sister, who had severe physical and learning impairments. Fazila was a carer for her sister and her mother, who became ill during the research. She also performed a number of household duties:

'Tve got to look after my mum and help her washing up and drying up and wash clothes, she can't do it herself.... I look after my sister as well. Sometimes my mum do it. The lady comes in the morning, and at night I do it... I get her changed, and then get in the bed, and after she's gone to sleep I go downstairs, do the washing up and tidy up, and then I go to sleep.'

Fazila equated autonomy in the home with domestic chores and said she liked it:

'T'm clean like that, not messy. It's not good if someone comes in your house and your house is a mess. Got to look nice.'

At other times she seemed to resent looking after her sister, and complained of not sleeping well on the couch (where she had to sleep for a while so she could attend to her mother).

Housework and caring seemed to be the family's expectation. Her responsibilities were outside of her control: 'I have to work you see, that's not up to me, I can't worry about that.'

Fazila knew she was treated differently from her siblings due to her impairments:

'You see I got two brothers, my mum and dad, I can't interrupt them talking... I got to be quiet. I don't feel down, that's not what I feel like. I feel like if I was like my brothers... they're clever. I'm not clever.'
Fazila attended 'F' day centre and went nowhere else. Towards the end of the research she had the opportunity to go to 'G' People First. She had wanted to go for some time but her parents had not allowed her. Fazila said she had to stay in with her sister ('I don't blame my sister'); if her brothers went out she had to stay with her parents, and vice versa.

'I want to go to some different places, like a club, go outing and that, I haven't got that, no life to go anywhere, stuck in there. It's not boring, I have to say. But people in here (the centre) they do something, they go clubbing, and I don't get that. Stuck indoors, that's it.'

She also suffered some racism on the centre transport, which she gave as a reason why her parents did not let her go out.

Fazila did not let me meet her parents. She said they could not speak good English, but I wondered if, as with Kevin, there was a degree of self-protection involved. She had not yet told them about her involvement in 'F' group, and there was significant tension between the day centre and home, so I think keeping me from them was conflict-avoidance. The tension seemed to me to be rooted in a number of things: her parents placing restrictions on her, differing perceptions of her support needs, and a lack of cultural understanding on the part of the centre.

One example of the conflict between the centre and home was when her watch broke. Fazila bought a new one with money from the centre and her parents rang in to complain. She explained this to me in this way: 'I didn't want a watch, they forced me to go'. Fazila wanted work experience but was frustrated by differing perceptions of her support needs:

'[To] my mum and dad I mentioned work experience. They said to me, "Your eyes really bad".... "You can't go on buses." Because I got short-sighted, and I can't see very well. But [the centre] don't understand, you see. And they won't listen to me at all. Same thing all the time, and I'm really fed up with it.'
So her family would not allow her on buses, but she perceived that the centre were at fault for not recognising her situation and providing the support necessary.

Fazila's attitude changed during the research. She originally felt restricted by her family while the centre were offering her more opportunities (though was frustrated at the lack of the work experience). Some months later, the position reversed: her family she saw as understanding and the centre were causing her trouble. She knew this was a change of approach: 'Because improving, my family's improving to me. They're helping me very much.'

By her descriptions, however, the situation did not seem to have changed, except that she was now sleeping on the couch. This change in view could simply be indecision: we all say different things at different times depending on how we feel. However, Fazila's change in attitude also struck me as a pragmatic way of dealing with the ongoing tension. At first the centre were good because they were giving her opportunities which her family were trying to restrict; but this led to too many problems at home, so she dealt with it by accepting her family's perspective. The influence of family was much stronger, and perhaps the centre was easier to rail against, with less at stake. The co-researchers commented that she did seem to be too restricted by her parents (in fact they said she seemed like 'a servant'), but there was perhaps not much she felt she could do about it:

'It's sad, but she has to deal with it by accepting it. You can't fight all your life unless something's going to change.'

I also speculate that the change in attitude came about when her future role in life became clearer to her. Fazila had begun by saying she wanted to leave home, which would require an arranged marriage:
'Because we're family, and anybody's not allowed moving to another house alone. Not alone, because we get married first, then we are allowed to move house.'

Fazila said she wanted an arranged marriage like the rest of her family:

'T'd like to get married. Need to find a boyfriend first. It's religion see, my religion. I find a boyfriend first, with a degree or whatever comfortable for me, his age and things, arranged marriage.'

She said she did not know if it would happen, and suggested that her impairments would make it less likely.

Later, in line with her change in attitude to her parents (and the move to the couch), she said she had no wish to move out, her role was to stay at home and help. She saw for herself a life of caring for others in her family:

'No, I don't want to leave home. I got to look after my parents, or my sister or brother. I can't leave home. I never can be separate. To help out. Because my mum's ill, my dad's ill. Can help out, do some manage to my mum.'

This was not presented as a negative prospect. There are gender as well as cultural issues here, with Fazila seeing caring as an important woman's role: being an adult was 'to do typing, caring.' Feminists have traditionally denigrated caring as exploitative, but for disabled women it may be important and confer status (as found by Barron, 1997).

Fazila's experience seems to fit with Brannen et al's connectedness (1994). Her reference to racism on the centre transport may be significant in shaping her views of her family. Racism in society may make the wider world a dangerous and threatening place while her family seem to be secure. An exploration of black people with learning difficulties' experience of racism is uncommon, though has begun (e.g. Black People First, 1994; Walmsley and Downer, 1997).
To Fazila, independence was 'doing something in your life.' She saw independence as achievable within the home:

'I don't want to leave home. Want to stay with my parents. And independent, go out, do your own thing. Like going on the buses and that.'

She was certain of her adult status. She said she was an adult and was treated as such at home but not at the centre. 'I'm not a kid, I'm not a child, I'm grown up.'

**Michael and Mr and Mrs Banks**

Michael and the Banks' story illustrates the families where parents plan for a move (like some of Wertheimer's respondents), showing that this is not without its dilemmas and fears. Adult status for Michael was still contested. This story also highlights class differences.

Michael's parents wanted him to have a good life. Michael was confident he would get the life he wanted, but there was one exception to this. He said he would like to leave home at some stage but said early on in the research that if his parents did not want this he would stay at home. He seemed unperturbed by this apparent contradiction, and I wondered if this was at least in part because his older brother was still at home. He said, 'My place is at home where my parents and my brother is.' Michael was still young, and he was looked after and comfortable at home in a way that did not mark him out from the rest of the family because they had an au pair.

Meanwhile, Mr and Mrs Banks had plans for him to leave home - they had started to look round places, and had a time-scale for introducing ideas to Michael. Unlike Mr Shah, they had no concerns about lack of provision. As part of the Jewish community they had access to
Jewish housing support schemes, and had sufficient finances to pay if necessary. Mr Banks said it was possible for Michael to change the plan. He said he would like Michael to initiate the process of leaving, though he saw it as in the future:

'As time goes by he may, through someone else mentioning it that lives in one of these places, and he might think it's time he left home. Now that won't happen till [the others] leave home.... He may feel, "Well I'm 20-odd years old, I want to leave home"... And I'd much rather that. He could leave home like they had.'

Mrs Banks said she wanted her own life but would like Michael to stay as long as he was autonomous in the home, though she was happy to have a long-term plan for him to leave if that was what he wanted. She said she found it very hard to let go, but she also did not want the restrictions on her own life:

'Independent within the family. If I could get to that stage I wouldn't dream of him going away from home... I think I might be a bit selfish and say if he wasn't independent then I would feel very held back and I wouldn't like that.'

Michael saw independence as achievable at home: 'Being by myself in the house, going on buses, going shopping.'

Towards the end of the research his brother left home and this did make the issue more immediate for Michael. His parents had planned for him to go into a group home in five years, but he suddenly suggested this be reduced to two years. Mrs Banks was taken aback by this change, although Mr Banks had professed he expected it. It seemed to bring the long-term plan much closer. (The research ended before any long-term effect could be seen.)

Michael had his 21st birthday during the course of the research. He still went to a youth club, and at different times he defined himself as a boy and a man. He said he was treated like an adult, giving the example of doing things for himself in the home. He said, 'I am very sure I am treated like a grown up'. Mr Banks constantly referred to Michael as a 'kid' - but said that
was the way he talked about everyone young. When I probed, he admitted he did not see
Michael as an adult, but did see it as their job to make him one:

'Chronologically he may be an adult, but I think from his development point of
view he's a child. And we're trying to make him an adult because we're instilling
in him things he can and shouldn't be doing and what have you. Michael's trapped
in the middle there somewhere between a child and an adult. But that's only
because of his mental abilities, it's not because of his aspirations, it's not because
of us keeping him down'.

Michael defined adulthood, in part, as 'going to work'. He had a Saturday job and had hopes
for a full-time, paid job out of it. Mrs Banks saw Michael as having a job in the future and
was proud of his college work:

'I hope he will get some sort of meaningful job, because he is quite capable of -
certainly work. Because you only have to show Michael once and he's quite able
to do it.'

Mr Banks wanted him to have a job that was gainful, fulfilling and enjoyable. He wanted him
to have self-respect and purpose.

Michael said he hoped to get married in the future but he did not have a girlfriend yet. He
thought his parents 'would be very happy' if he got married. Mrs Banks was happy for him to
get married or live with someone, if it was in a sheltered environment. Her approach to his
sexuality, however, was more appropriate to a young teenager:

'It doesn't appear that Michael is very sexually aware. He knows about it and he
-says he wants a girlfriend, but I don't think it's a sexual thing, it's just that he
wants to be like his brother and have a girlfriend. It was a couple of years ago,
this girl used to come, and she was much more sexually aware than he was. We
had to watch her actually! Had to be careful... We wouldn't leave them in the
house on their own.'
Michael had vague hopes for children, seeing his future as 'happy, getting married, having children.' Mrs Banks was open on the question of children, though recognising the difficulties:

'It would depend on what the girl was like. You can't say no, you don't know what will happen, it's hard to say. I don't know. I'd need a lot of thought about that.'

Mr Banks said they were fortunate that Michael was impotent. He thought Michael would be a caring father but not capable.

4. Individuation and connectedness

A number of points come out of these stories. The first thing that stands out is the refutation of the stereotype of the parent holding on and the son or daughter pulling away. In fact only one respondent, Esther, was in this situation - and she was the one who moved on during the research. This point endorses the findings of Wertheimer (1989) that many parents want independence, and that separation is difficult for both parties.

Secondly, the assumption that the parents are the only active players is also refuted. Echoing Richardson and Ritchie (1989), the parents felt that they were the ones who had to initiate a move. However, I think it is a mistake to assume that this was because the people with learning difficulties did not try to initiate moves themselves. My respondents did - but sometimes they were not heard by their parents. Mr Shah appeared to sweep aside Daniel's aspirations. I felt that to him it was more important to maintain his idea of Daniel as not thinking, than to face up to the challenge of making changes. The Banks said they wanted Michael to take the initiative but assumed he would not - they were unprepared for Michael suggesting he leave home. The wish of Katya and Fazila to stay at home was not through lack
of thinking about it - they had thought about it and knew what they wanted. I suggest that because of the assumption of parents, services and society (and researchers), that the parents have to initiate and the people with learning difficulties do not, signs of people doing just that are overlooked.

An important point is the similarity between these experiences and those of any family - feelings of guilt, hopes for children to have a good life, fears that they will not cope, different aspirations between parent and child. There are differences, however, particularly with the time-scale concerned and in comparison with siblings. The time-scale was slower for all my respondents than their siblings. It is noticeable that the assumption of all the parents - even Eva, who was so keen to resolve the issue - was that the move to leave home would be 'in the future', either at some unspecified time or with a safe time-scale of several years.

In all these instances, there were siblings who had left home, who had work, and were married with children already, and the achievements of siblings had an effect on the person with learning difficulties. This was with the exception of Katya, who saw herself as having different ambitions - was this because she felt she could not do it, or was it a sign of her confidence that she did not feel the need to just follow her siblings?

My findings do support there being considerable fears and dilemmas for parents beyond the 'normal' experience, thus supporting the finding in chapter 8 of the experience of both difference and similarity. There were fears about safety, support levels, and not having had enough help to deal with these issues (supporting Richardson and Ritchie's findings (1989) in regard to failure of services, and also supporting Todd and Shearn's argument (1996a) for
parents to receive different kinds of help at different stages). Michael's story suggests that difficulties regarding support are related to the economic circumstances of the families.

An important point in terms of self-advocacy that flows from this is the question of where the control lies. As seen in chapter 8, the respondents had control in their daily lives but this was allowed control, and there was a suggestion that it would be harder to allow people to have control over the bigger issues. The sense of control in each of these stories, in my view, is that it remains in the hands of the parents. The only parent who lost that control was Mrs Cohen (see chapter 8), interestingly when she herself was in a condition society deems as being in need of care and control - old, frail and ill.

With Katya and Eva, the distinction between autonomy and independence is important. Katya did not plan to leave home, while Eva was preparing for separation. To Katya, 'independence' did not mean leaving home, but meant autonomy. The distinction between autonomy and independence is also important with Fazila. She intended to stay in the family home as a carer, but still considered that she could be autonomous. Additionally, there was the issue of different value systems. Not all families aspired to independence; for Fazila, her role in the family appeared to be more highly valued. There is clearly a cultural point here. There is also an interlinked gender issue, with Fazila seeing caring as an important woman's role.

Other markers were also difficult. As Wertheimer (1989) suggested, work was easier for some parents to deal with. Katya's and Christine's experiences show the value of work - a symbol of adulthood and independence, a conduit to friendship, confidence, security, money, and respect. The Banks wanted Michael to have these benefits; to have self-respect and
purpose. Mr Shah stands out as not thinking Daniel could work, though two of the other parents not case-studied here, Tracey and Jason's parents, felt the same way. Their reasons were that their offspring were not capable, and that they enjoyed the day centre. In my view, these feelings about work were connected to those about leaving home: to do with fear of change, and in the case of Mavis and Tracey, interruptions to the plans. I could not speak to Mr and Mrs Begum, but I gleaned from what Fazila said that they probably did not like her aiming for work - perhaps it would interrupt her care role.

Although most of the respondents with learning difficulties were keen to talk about relationships and their aspirations to marry or live with someone, sexuality itself was a difficult area, embarrassing for people to talk about. None said anything about homosexuality. Parents all claimed to want their offspring to have relationships. I think part of this was again 'one day in the future', but also an indication of parents' desire, as suggested by Richardson and Ritchie (1989), to have someone who would care about their child in the future.

Parenthood was a different matter again. Mrs Cooper vaguely hoped that Jason would have children, I think part of a general wish that he could be like everyone else; the other parents gave it more serious thought. Out of a desire for their offspring to be happy and have the life they wanted, three sets of parents - Eva, the Banks and Mrs Papandreos - did not rule it out completely. Nevertheless they had grave doubts. Eva, for example, was concerned about the reality that would face them (a reality graphically recorded by Booth and Booth, 1994). Mr Banks' concerns were that Michael would be caring but not capable, confirming and extending to men the point made by Williams (1992) and Brown (1994) that women with learning difficulties have historically been seen as unfit parents. With my respondents, there
was a gender split regarding parenthood: the women mainly did not want children, while the men had vague hopes. The women saw children as too much to cope with, and they saw little opportunity, and I speculate that they had been encouraged to think so. The men seemed not to have considered the coping aspect.

I use Brannen et al’s concepts of *individuation* and *connectedness* (1994) to help understand these experiences. Individuation describes families that value independence and prepare for it; connectedness depicts families that want to stay together and value independence less.

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<thead>
<tr>
<th>individuation</th>
<th>connectedness</th>
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<tr>
<td>Christine and Vanessa May</td>
<td>Kevin and Mr and Mrs Waluk</td>
</tr>
<tr>
<td>Anita and Mrs Papandreos</td>
<td>Fazila and Mr and Mrs Begum</td>
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<tr>
<td>Tracey and Mavis and Mr Barker</td>
<td>Jason and Mrs Cooper</td>
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<tr>
<td>Michael and Mr and Mrs Banks</td>
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Three families are not in this scheme, because they are a mixture. Eva espouses individuation, but Katya wants to stay in her current more connected arrangement. On the other hand, Esther valued individuation but Mrs Cohen wanted to remain connected. With Daniel and Mr Shah it was not so much Daniel wanting individuation and Mr Shah wanting connectedness - though that is there - but that they were both pulled both ways.

This fits with the frameworks in the previous chapter. At the risk of being too bald, I suggest that the captivated parents have a connected outlook, which means they hold on to parenthood and close family life, creating dependent or mutually-supportive families. The captive families have an individuation outlook, which means that they want their own lives, and achieve such by creating supportive families. There obviously are overlaps - no people
live out their lives in categories - but one of the values of bringing together these frameworks is to take the negativity out of the notion of being captive.

I want to make a final point in this section. Eva sees Katya's desire for autonomy within the home, for connectedness, as a failing of self-advocacy. I suggest that perhaps the failing is in not making the distinction between autonomy and independence: self-advocacy champions autonomy but uses the language of independence, and thus perhaps falls into the trap of advocating one particular form of autonomy. While this overlooks the distinction, it also overlooks different value systems. It may be that this is connected to the observation of Walmsley and Downer (1997) that the self-advocacy movement is still dominated by white men. Self-advocacy perhaps reflects the value systems of white men; and by being seen to espouse independence rather than the broader autonomy, possibly prevents full participation of women, people from different ethnic groups or those with different values.

The next section develops the issue of adult status and the relationship of this with the identity of learning difficulty.

5. Identity

Wertheimer (1989) suggests that disabled people slip in and out of adult status, a point also made by Holman (1981). Jenkins, on the other hand, suggests that people with learning difficulties are not ascribed adult status at all (1989). My conclusion on this from my findings is that my respondents were neither slipping in and out of adulthood nor denied it completely.
they seemed to be in a kind of 'suspended phase', wavering on the boundary into adulthood but not reaching it fully.

It is appropriate to look at how the label of learning difficulties itself interacts with this identity question. Chapter 3 argued that learning disability is not synonymous with adulthood. Jenkins demonstrates how medical, psychological and behavioural models, law and popular conception all point towards people with learning difficulties being the 'eternal child', for example, by using mental ages. Chapters 2 and 3 showed that while policies such as normalisation and the self-advocacy movement fight a battle in the opposite direction, these are up against powerful ideas which encourage the parent to see the adult with learning difficulties as a child. Community care can reinforce this, with the roles of care and control carried out by institutions being passed on to families.

In the main, my respondents with learning difficulties saw themselves either as adults or in transition - despite the treatment they sometimes received. They saw the traditional markers as signifiers of adulthood and in the main aspired to them, but the fact that they had largely not achieved them did not deflect from their self-image. Clearly a range of factors affect people's views and it is not straightforward that being treated like a child, or not leaving home or getting a job, automatically means you see yourself as a child. The 'robustness' (Jenkins, 1989) of the adult identity as a desirable goal in society must be very influential.

In general, the parents wanted to protect and keep their sons and daughters safe. They tried to see them as adults, though in their minds they were children. Part of the problem may come from the interpretation of adulthood as being certain behaviours - hence Eva saw Katya as an
adult because she behaved like one; Mr Shah thought Daniel behaved like a three year old. There is a sense in which many of the people with learning difficulties were perceived as halfway between children and adults, as expressed by Mr Banks (an echo of Todd and Shearn, 1997). This view is backed up by Sharon, one of the advisers:

'There's seems to be a suspended phase of not quite reaching adulthood.'

I use Brannen et al's concepts of ascribed and achieved adulthood (1994) to help illuminate the development of adult status within the family. There was an assumption by some parents that they had to ascribe adult status. This is similar to the question of independence: perhaps they did not always see the developments their sons and daughters made themselves. Some parents hoped their child would achieve adulthood in a 'normal' fashion. Others hoped for this but recognised there would probably be a mix. The social identity of learning difficulty makes it hard for people so labelled to achieve adulthood, and they perhaps need some ascribing.

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<th>expect their child to achieve</th>
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<tr>
<td>Eva Klein</td>
<td>Mr and Mrs Banks</td>
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<td>Vanessa May</td>
<td>The Waluks</td>
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<td>Mrs Papandreos</td>
<td>Mavis Barker</td>
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<td>The Begums</td>
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Vanessa and Christine's relationship appeared to be based on the expectation that she would achieve adulthood in a 'normal' way. Vanessa described their arguments as the same any mother and daughter have during the transition. With Christine still young, this expectation had yet to be tested in practice. Further down the line, Eva's frustration in part came from wanting Katya to achieve independence herself and resisting ascribing a lifestyle.
Missing from this framework are those parents who wanted to keep their son or daughter as a child. There was a difference between those parents who wanted to see their offspring achieve adulthood, could see their development and wanted them to experience a 'normal' transition, and those who left them to achieve adulthood on their own because they were not willing to ascribe adult status. They insisted on seeing their son or daughter as a child despite the evidence to the contrary.

**hold on to them as a child**

Mrs Cohen  Mr Shah  Mrs Cooper

I have suggested that an important factor which prevents my respondents from being fully adult is the social identity of learning difficulty. Chapter 3 showed that there is a strong element of claiming normality within self-advocacy. My respondents with learning difficulties and their parents tied self-advocacy to what is 'normal'. Tracey said, 'You're trying to be like some people outside, you're trying to be like them'. Mrs Banks raised the normality of self-advocacy unprompted, relating it to what her other children did.

Chapter 3 debated whether in claiming normality, people with learning difficulties are attempting to pass as normal, as Goffman suggested (1968), are in denial, as argued by Edgerton (1993), or are redefining their identity, as argued by Shakespeare (1996a). Chapter 3 showed that some parents try to shield their sons and daughters from their social identity, but they still acquire an understanding of the social implications of that identity through their daily experience (Todd and Shearn, 1997). I suggest that this is the case with Jason. He was not aware of his label learning difficulty and he disowned the label 'disabled', but he knew
there were things he could not do and that his mother had to help him. Jason probably does fit Edgerton's ideas of denial - he simply did not know about his social identity and claimed he was 'normal'. His claim to normality was an unconscious one.

The others, however, were different. Chapter 3 suggested that participating in self-advocacy is one way in which people with learning difficulties become conscious of their social identity, and this was certainly the case with all my other respondents. (I think Jason's situation was in part because 'C' group was formed especially to take part in a national project rather than to develop self-advocacy, and so such issues were not as explicit within it.) In my view, their claims to normality were redefinition rather than denial or passing. They all knew they were labelled as having learning difficulties, they knew they had impairments and needed help, but they did not accept the label. I use Christine May and Michael Banks as examples.

Christine May

Christine knew that because of her epilepsy she needed people around her. She said if she had not had special help, 'I wouldn't have got this job.' But she did not accept that she should be labelled, because it meant that she was assumed to be unable to do things:

'Society classes certain people like a learning difficulty, but I think to myself that I haven't. Maybe I have got certain things that may be I don't understand or need help with, but I wouldn’t class myself as someone with learning difficulties. I can do everything the same as everyone else. I mean, because I've got epilepsy, I wouldn't class that as like an illness or anything. Because it doesn't affect any part of my life really. Certain times, sometimes when I have a fit, attack, most of the time it's while I'm sleeping. And when I do have them my mum's always there and I'm not really aware of it. So it doesn't affect me, like doing things or working or doing sports or things like everybody else.'
This was not just that she was attempting to distance herself from other people with learning difficulties (as Edgerton would suggest). She had strong views about the treatment of people with learning difficulties:

'Everyone should be treated fairly, they shouldn't really judge people or put a label on everybody. Like people with learning difficulties put all in one group or something, because if they do that people will think they're different from other human beings, like people with no problems at all, and they're the same as everybody else, there's no difference.'

Christine rejected a duality of either having or not having learning difficulties, and instead placed herself on a spectrum along which we all lie.

**Michael Banks**

Michael was conscious of his difficulties:

'I can't wash up or dry, because my hands need to be steady and things might drop on the floor.'

The Banks got involved in medical research which might find a cause of his impairment. Of this, Michael said, 'It will be good to know. I've always wondered what was wrong.' Although he knew he had something 'wrong', he did not accept the label of disabled:

'I can go out, I can cook, I can make tea, I can have a bath myself. I don't find that disabled... I'd say that was very normal.'

Christine and Michael were aware of their limitations and of their need for support, but rejected the label. Christine was vociferous in her views of the way society treats people. The problem, as indicated in chapter 3, is that adulthood and the label do not rest easily together. At least some of my respondents rejected the label learning difficulties and claimed adulthood instead.
Self-advocacy is part of this process: it is a normal, adult thing to do, and appears to play a part in claiming a particular identity. It is, as chapter 3 suggested, both part of being an adult and a route towards it. Having adult status ascribed leaves parents still maintaining control. Participation in self-advocacy may give some people the push to achieve rather than have adult status ascribed. This does not mean, of course, that self-advocacy makes one an adult. As Susan, 'F' day centre manager said, self-advocacy on its own does not necessarily result in parents seeing their child as an adult. They may still see them as a child, 'but a cocky child!' It is a dialectical process, part of being an adult, part of a renegotiation.

6. Conclusion

This chapter has explored the interlinked issues of autonomy, independence, adulthood and self-advocacy. My findings have tended to support much of the (fairly sparse) literature on this subject. The most important points I have reinforced are the refutation of the stereotype of parents holding on and children wanting to leave (Wertheimer, 1989), and the experience of both similarities with other families and specific difficulties (Richardson and Ritchie, 1989). Also supported are the points by Williams (1992) and Brown (1994) that gender differences are important regarding aspirations to caring, both in terms of caring for parents and having children. Women with learning difficulties seem to be acceptable as carers of parents but not as carers of children.

My work has also thrown up new points. People with learning difficulties are active players in the decisions to move on - parents (and services, etc.) may assume that they have to take the initiative, but in fact the people with learning difficulties are trying to do so too. Nonetheless,
the question of control still seems to be fairly securely in the hands of parents, until they themselves become frail and deemed to need care and control.

The distinction between autonomy and independence is important and a potential source of conflict. Different value systems are at play which mean that not everyone aspires to independence. Self-advocacy has perhaps championed independence at the expense of other values, thereby leading to disillusionment (on the part of people like Eva) and possibly the exclusion of particular groups of people.

Adulthood is difficult for people with learning difficulties to achieve and they seem to be in a suspended phase on the boundary between childhood and adulthood. The social identity of learning difficulty is a significant factor in preventing the assumption of adult status. Some people with learning difficulties are re-identifying themselves as part of their involvement in self-advocacy, rejecting the label learning difficulty as incompatible with their aspirations and claiming adulthood instead.

This chapter is the last to address findings from the research. I now move on to conclude the thesis.
This chapter reviews the thesis and draws together the research findings into some conclusions. I assess the contribution of my work to current knowledge and practice. The thesis ends with recommendations for further research.

1. Disability theory

The thesis opened with a discussion of disability theory and its application to people with learning difficulties. The social model of disability developed by disabled theorists such as Finkelstein (1980), Abberley (1987), Oliver (1990) and Barnes (1996) has, I believe, much to offer the understanding of learning difficulty. The value of their materialist approach is in placing experience in its historical, economic and political context. The social model explains disability as a social construction and as oppression. In shifting the emphasis from individuals and their impairments to disabling environments, the theory is particularly useful in explaining the oppression of people with learning difficulties and their social identity as people seen to be in need of care and control.
However, as discussed on pages 25-6, learning difficulty is marginalised in the debates and the social model is only occasionally applied to people with learning difficulties. I have found that applying the model to the experience of learning difficulty has required a dialectical approach (in other words, an understanding that experience is formed through a number of interacting and contradictory material and social factors). The social model argues that it is not the individual’s impairment that disables but society; however, as seen in chapter 2, there is debate developing around the reality of impairment, and the limitations and personal experiences impairment can mean (for example, French, 1993a; Crow, 1996).

As I argue in chapter 2, it is not a question, in my view, of having to move away from a materialist standpoint to incorporate the personal experience and impairment. As Abberley explains (1996), impairment itself is materially and socially constructed. A *dialectical* materialist approach avoids a crude opposition between the person and society: people are social beings and experience is a product of interaction between personal and social, agency and structure. In my research, the reality of impairment was confronted and tackled in relation to co-researching with people with learning difficulties (see chapter 5). My experience has shown an interaction between both social barriers and limitations of intellectual impairment. (The risk in acknowledging this is the possibility of opening the door back to individual models, which I would vigorously oppose.) This complex and tentative understanding of learning difficulty has significant implications for self-advocacy.
2. Self-advocacy and families

Through the review of self-advocacy literature, its claims, history and influences, I have demonstrated that self-advocacy is about the whole of life, intimately linked to achievement of control, autonomy and adulthood. In its meanings and principles it is both explicitly and by implication to do with families. Nevertheless, I suggested that its history has been influenced by the individual model of disability and by the perceived need for care and control. There has been significant intervention by services and service agendas, which has meant in practice neither discussion of families nor the transfer of self-advocacy to home has been a significant feature. The policy contexts of user-involvement, normalisation and community care were discussed and pointed to the influence of service interests in determining the practice of self-advocacy. The role of advisers is under-researched and my work explores this neglected area.

Chapter 3 discussed families and noted a neglect within family theory of families with disabled members and families in which adults stay at home. While there are some useful models regarding family types and attainment of adulthood, there is a sense in which families with a person with learning difficulties are set apart. Within the literature on families with members with learning difficulties, there is a tradition of focusing on negatives and reinforcing the pathological notion of a separate 'handicapped family'. However, there is a growing number of studies which take a more rounded approach, reflecting the heterogeneity of real experiences. Within this trend, there is only a little attention paid to the views of the people with learning difficulties themselves.
I reviewed the literature on adulthood and found that it focuses on routes and markers not commonly open to people with learning difficulties. I discussed the difficulties in achieving adult status and showed a lack of compatibility between the status of adulthood and the status of learning difficulties. I returned to community care and theories of care and control to demonstrate that the controlling function of families continues into adulthood in those families with a person with learning difficulties. My work draws together research on these different areas to come to an understanding of the attainment of control and adulthood within families when the adult child remains at home. In place of care and control, self-advocacy argues for autonomy; instead of being like children, self-advocacy claims adulthood. In this way self-advocacy potentially challenges the expected roles and relationships within families. However, I suggest that it is up against powerful forces, in the shape of service control and influence over self-advocacy and the experiences and expectations of families.

3. Heterogeneity, difference and normality

The traditional concept of the 'handicapped family' is undermined by my research. The first point to make is that all my respondents' experiences were different: stereotypes of controlling parents holding back their adult children were not found (echoing Wertheimer, 1989). There were elements of this in each life story; but there were parents who pushed their sons and daughters to develop, struggling with feelings of guilt and protection. There were people with learning difficulties who did not want to let go; there were those who fought for complete independence and others who relatively passively waited to be done to; others seemed to have found their life's niche already in a companionate household or in a caring role.
The families I interviewed evidently experienced struggle and difference. There was dissatisfaction with the type and level of support, and the experience of isolation and empty lives. Supporting Richardson and Ritchie (1989), within these differences, there was the common thread of normality. Without doubt my respondents, both with learning difficulties and parents, were battling to cope with a series of material and social differences and barriers. However, so much of what they described is similar to the experiences of us all: family stories, teaching independence skills, the worries and arguments of reaching a new status and renegotiating roles. There is real struggle with material and perceived difference, but there is no dividing line which completely separates out families with disabled members from other families.

Another important feature is that lives change. The longitudinal elements of the work allowed this to come through. I have used the past tense throughout the thesis to convey this sense of change and that as the reader learns about the respondents things have probably changed again. People are not members of self-advocacy groups forever; they do not live with their families forever, however 'stuck' they may appear to be. Self-awareness changes, people grow up, thought processes become more sophisticated, views change. This is not a sign of inconsistency in the reporting or failure of method, it is the reality of life. What is also positive is the evidence through Esther that resolution of difficulties is possible.

4. Principle and practice

The thesis has demonstrated a basic contradiction in the experience of self advocacy. I used the distinction between principle and practice to show that while the meanings and principles
of self-advocacy apply to home life, practice does not consciously transfer self-advocacy to home. The service influence is demonstrated in a second distinction between independent and service groups, with the former more likely to talk about and communicate with families. The role of advisers was analysed and, I suggest, is decisive in the agenda of self-advocacy. While some advisers were working to the individual model of disability, some were grasping toward the social model. However, I suggest that the service influence was sufficient to outweigh much of the effect of an independent adviser. While the advisers and services had control and influence, the people with learning difficulties also exerted control, particularly over the transmission of self-advocacy to home. Privacy was important to the respondents, both as a right to autonomy, and as a strategy for dealing with conflict.

All parties recognised the importance of families understanding self-advocacy in order to help the people with learning difficulties to speak up and achieve some control, but advisers and people with learning difficulties wrestled with the apparently contradictory need for privacy. As I showed in chapter 7, the distinction between principle and practice could be utilised to good effect if it were made in relation to the knowledge parents receive, so that parents are informed about self-advocacy but not the group itself. What is clear is that the parents I interviewed supported the concept of self-advocacy, even if they did not know about their son or daughter's involvement, and would have liked to know more to support it better. Some of the people with learning difficulties appeared to believe that if their parents understood self-advocacy, their right to privacy would be reinforced rather than compromised.
5. Control and autonomy

Self-advocacy did impact at home. In some instances it led to problems, yet mostly positive benefits were recognised. All the people with learning difficulties felt that they did speak up at home and had control over their day-to-day movements. When it came to the bigger issues, such as relationships and leaving home, families found these issues more difficult. There is a sense in which the day-to-day control that all parties describe at home is allowed control, and that real control still rests in the hands of the parents. When we come to the steps which would take people further away from that control it is much harder for the parents. Nevertheless, this does not mean that they all cling on and hold people back. Chapters 8 and 9 both demonstrate the efforts of families to overcome their feelings and to help their sons and daughters to autonomy and independence.

I have used different models to help explore the experiences of families. Todd and Shearn's captive and captivated (1996a) and Winik et al (1985) and Walmsley's supportive, mutually supportive, dependent and conflict ridden models (1996) have helped illuminate control and autonomy at home.

6. The transition to adulthood

The findings support the link between self-advocacy, adulthood and independence. Brannen et al's achieving and ascribing formulation (1994) is particularly helpful in looking at the attainment of adult status for a person with learning difficulties who stays at home. I have suggested that some of my respondents, while recognising their difficulties and support needs,
rejected the label learning difficulties as incompatible with their aspirations and claimed adulthood instead.

Self-advocacy is a challenge because it pushes against the care and control function of a family. In its literature, conferences etc., self-advocacy propagates adulthood and independence and champions leaving home. This is necessary in order to challenge the role of the family, but I contend that it does not reflect the reality of aspirations and experiences. One of the things my research highlighted was that families do not all fit the stereotype of struggling person with learning difficulties and restricting parent - only one of my respondents fitted this stereotype and she was the one who left home. Brannen et al's individuation and connectedness (1994) have been useful in exploring this. The values of complete independence, autonomy and separateness are not necessarily desirable to all families or individuals with learning difficulties. There are families in which connectedness is more important.

Eva sees Katya's lack of will to leave home as a 'failure' of self-advocacy. Is it? Or is it a failure of the self-advocacy movement that it does not allow for different values? This is particularly important regarding different cultural expectations, for example, in Asian families (Brannen et al, 1994). I suggest that this goes back to the question of the difference between principle and practice. The meaning of self-advocacy in its simplest form is speaking up for yourself. This should mean that people with learning difficulties develop lifestyles of their choosing, not that they have to forge a separate life. Disability theorists have emphasised the distinction between autonomy and independence (e.g. French, 1993b). Self-advocacy claims
autonomy but uses the language of independence, and in so doing may be excluding some people.

7. Gender, race, age and class

Some gender, race, age and class issues are raised by my research. Gender differences were generally not significant on issues such as leaving home or housework, unless combined with connectedness. Gender was an issue in regard to caring. Fazila Begum was expected to be a carer in her family, and saw caring as appropriate work. The caring issue was also evident in regard to parenthood. The men were able to hope for children without considering coping; the women saw (and I speculate had been encouraged to think) that they would have to cope, and believed they would not be capable (as suggested by Williams, 1992). There was also a gender issue with Jason Cooper, whose mother wanted him to get married in order that he would continue to be looked after. She seemed to see this as any wife's role.

I used Brannen et al's concept of connectedness to help illuminate relationships when an adult stays at home, but the original use of the formulation was with parents born outside the U.K. This aspect is clearest with Fazila, but there are elements of this with Mrs Cooper, from Barbados, and Kevin's Polish parent. I have pointed out above that the emphasis on leaving home in self-advocacy does not take account of different values held by different cultures.

Age was an issue with Esther, who was retired and therefore without the same aspirations to work as some of the others, and with Anita who was clearly battling through adolescence and had not yet faced the challenges of some of the other respondents. I have found, however,
that most of my respondents experience a suspended phase, despite being in their 20s. The class difference is clearest with Michael Banks, for whom being looked after was something that all family members shared because of the *au pair*, and for whom future finance, housing and support were easier to plan. This contrasts with Mr Shah, for example, who could see no realistic way of providing Daniel with decent support and living conditions in the future.

8. Double lives

The advisers pose the question: did my respondents lead double lives? On the surface, some did: Esther, affectionately known as 'God' amongst some users in the day centre but portrayed as incapable at home; Kevin with his secret life; Fazila with the centre and home pulling in different directions. But it seems to me that the 'double life' idea is not straightforward, and not a constant state.

As expressed by Eliza, one of the advisers, self-advocacy involvement will impact at home, consciously or not. A new experience will inevitably have its effects on the individual and other aspects of their lives. This does not necessarily mean that self-advocacy transfers to home in a smooth fashion. It could, if an individual lives within a family which already respects and encourages them to speak up and grow in control. This can be both when the self-advocacy involvement is known to the parents, for example, with Michael and Christine, or when it is not known, for example, with Anita and Tracey. This does not mean even then that the smoothness cannot be disrupted - such as when the time-scale for plans is shortened.
Equally self-advocacy can cause conflict, whether conscious or not. Mrs Cohen did not know that Esther was in a user group at the centre, but she did know that the centre was 'putting ideas in her head' about leaving home. Mr Shah did not know about either 'F' group or Daniel's aspirations for the future, but they still caused conflict within the family. Kevin's involvement, on the other hand, had been known by his parents and in their view had a negative effect to the extent that they tried to stop it. So the group was now a secret, but Kevin's leadership role within the service must still have affected his confidence and outlook at home. For both Kevin and Fazila, the double life seemed to be a strategy for dealing with conflict, a compromise position to make life run as conflict-free as they could manage. For Esther, however, the double life was far from this - it was a cause of constant irritation and a spur to grasp the opportunity of her mother's illness to move out. In the case of Daniel and Katya, however, the conflict rumbled on. The important point is that families are all different and need different kinds of support and information.

9. The co-researchers' criteria

The co-researchers believed that self-advocacy should take place everywhere. They anticipated difficulties in speaking up in families, which they thought would centre around parents not seeing their sons and daughters as adults. These two expectations were borne out in the research: the respondents saw self-advocacy as being about the whole of life, and the issue of adulthood was important in developments towards autonomy in the family home and independence from it. The co-researchers were pleasantly surprised by the support parents gave to self-advocacy and the day-to-day control the respondents with learning difficulties felt they had, but were not surprised that the parents allowed this control and retained ultimate
control themselves. The co-researchers emphasise the need for parents to know more about self-advocacy in order that they can understand it better.

The co-researchers' criteria were useful for exploring the experience at home. In chapter 8 I suggested that the co-researchers' expectations of sharing decisions, sharing the setting of rules etc. were not necessarily signs of the person with learning difficulties moving towards autonomy and leaving home. In those families in which the person did seem to be on this path, there were deliberate efforts by parents not to involve their son or daughter in everything in order to push them towards independence.

10. Methodology

My thesis has justified a qualitative, participatory approach. My work is built on developments in learning difficulty research which have moved towards relationship-based research and biographical methods. I have combined and built on lessons from feminist research, oral history, user involvement and disability research. My work is part of a pioneering trend to carry out participatory research with people with learning difficulties. This research has demonstrated the ability of people with learning difficulties to take part in the research production process and the value to research of their involvement. Chapter 4 discussed the distinction between participatory and emancipatory research, with participatory research being that in which researchers invite disabled people to take part in what remains principally their work, while emancipatory research is that controlled wholly by disabled people for their own ends (Oliver, 1992 and 1996; Zarb, 1992). I argued that participatory research is of value both as a route towards emancipatory research and in its own right.
As a non-disabled person, I approached this research with some trepidation, asking of myself the question posed by Drake (1997), 'What am I doing here?' My motivation to do participatory research came in part from this question, attempting to be clear whose side I was on (Becker, 1970). The work throughout was fraught with the ethical dilemmas discussed in Chapter 4, regarding using people with learning difficulties for my own ends, salving my conscience, etc. I have argued for a reflexive approach as a safeguard, with constant scrutiny of my actions and motivations. Non-disabled people dominate the debate around learning difficulty, and this has remained a dilemma for me. Nevertheless, as I discussed in Chapter 4, disabled people conducting disability research does not, in itself, resolve questions of power relations, a point made by Barnes (1994; discussed on page 119). Oliver and Barnes (1997) are very careful not to say that non-disabled people cannot do disability research.

I have raised questions about the compatibility of this approach and academia. Without major changes in research production, the demands and controls of academia will mean emancipatory research will lie outside its orbit. Nevertheless, there are steps that researchers can and should take to reduce the exploitative and disempowering aspects of their work and make research more participatory. Indirectly, academics can thereby assist the chances of people with learning difficulties acquiring the skills, knowledge and motivations to carry out emancipatory research.

My work has also raised a possible contradiction between qualitative methods and participation. The same arguments encouraged me to do both. In practice, qualitative methods, while appropriate for the subject and to ensure as non-exploitative an experience for
my respondents as possible, were in part disabling for my co-researchers. This is an issue I cannot resolve and which points to the need for further exploration.

11. Contribution of this thesis

The contribution of this work is manifold, to the fields of self-advocacy and families, to self-advocacy practice, and to methodology:

• Contributing to the analysis of learning difficulty in disability theory.

• Expanding knowledge of the experience and impact of self-advocacy into an entirely new area.

• Contributing to self-advocacy practice, with recommendations to self-advocacy groups and advisers on the nature of their communication with families. The findings have been presented in an accessible form in a report by the co-researchers, which we hope will inform self-advocacy groups, members, advisers and parents.

• Extending family theory to include families with members with learning difficulties, including those where adults live at home.

• Extending the literature on adolescence and adulthood to people with learning difficulties.

• Building on the small body of work which has looked at the perspective of people with learning difficulties on family life, particularly in relation to the transition to adulthood and establishment of identity.

• Adding to the growing tradition, in oral history and auto/biography, of recording people with learning difficulties' own testimonies.

• Developing reflexive practice in relation to participatory research with people with learning difficulties.

• Developing the theoretical discussion around participatory and emancipatory research.

• Raising questions for further exploration around the compatibility of participatory research with academia and with qualitative methods.
12. Further research

This research is in such a new area that the picture of self-advocacy and families has only
begun to be painted. A range of issues are raised within the work, all of which would benefit
from further investigation. In terms of disability theory, the application of such theories to
people with learning difficulties would benefit from exploration of the complex interaction
between social barriers and the delicate question of the reality of limitations from intellectual
impairment. Broad points raised in the findings relating to adulthood, identity, control and
autonomy require more development, to understand how they are experienced within families
and in interaction with other social forces.

Specifically in relation to self-advocacy, further exploration of its meanings, the question of
control over self-advocacy groups and the reality of self-advocacy as an agent of change,
would perhaps start to tackle some of the vital but sensitive questions raised by Aspis (1997).
More work of an in-depth nature is required to start to fill out the picture of the transfer of
self advocacy to home and its impact. A comparative study with people not involved in self-
advocacy groups would throw new light again on the impact of self advocacy. In addition,
the subject would benefit from action research with self-advocacy groups, to explore ways of
more actively encouraging the transfer of self-advocacy to home and assisting parents to deal
with new possibilities.

Participatory research with people with learning difficulties is in its infancy. I hope my work
can be of help to others in developing opportunities for people with learning difficulties to be
involved in research and for the boundaries to continue to be extended. The possible
contradiction which arose in this study between participatory research and qualitative methods would be particularly interesting to explore further. This would involve using alternative research methodologies and would enable me to develop further research skills.

I finish with the contention that the research fields of both self-advocacy and families, and the theory and practice of participatory research, are advanced as a result of this work.
Appendix 1: WHAT BEING A CO-RESEARCHER WOULD MEAN

Learning more about the research

Helping me find out about self-advocacy and families

Helping me to plan the research

Helping me to practice skills and try out the plan

Keeping in touch with the research as it happens

Helping me to understand the results

Meeting about once a month and other meetings at other times

WHAT WOULD HACKNEY PEOPLE FIRST GET OUT OF IT?

Taking part in research

Helping to find out things that will help People First and other self-advocacy groups

A report

Money - hopefully
Appendix 2: THE YELLOW BRICK ROAD

Diagram showing various stages and activities, including getting to know, learning, keeping in touch, planning, piloting, practicing, changing the plan, and finding people to take part.
Appendix 3: CRITERIA FOR SELF-ADVOCACY AND FAMILIES

1. Family talks, including knowing what's going on, family decisions, sharing feelings.

2. Treating you like an adult and with respect.

3. Control over money.

4. Having a choice about what you do.

5. Doing household jobs - and not being reminded all the time.

6. House rules being your rules as well as your parents'.

7. Being allowed to go out (even if you do have to say when you'll be back).

8. Being listened to and given time.

9. Personal changes that happen to you because of self-advocacy should be noticed at home.
Appendix 4: RESEARCH RULES

1. Don't talk down to people.

2. Listen.

3. People with learning difficulties should have control of the research.

4. Parents should be treated with respect.

5. Don't tell others what respondents say.

6. Don't tell parents what people with learning difficulties say.

7. Don't tell people with learning difficulties what their parents say.

8. Don't treat respondents like objects.

9. Don't try to tell respondents what to say.

10. Don't go shy.

11. Don't use words that are difficult.

12. Don't lie.
Appendix 5: INTERVIEW CHECKLISTS AND QUESTIONS

PERSON WITH LEARNING DIFFICULTIES - INTERVIEWS 1 & 2

Chronology

pre-school
school
leaving school
work / day-time
social
friends
self-advocacy group

Family

relationship with parents
expectations of parents
relationship with siblings
treatment / life compared to siblings
coping
support

Identity

learning difficulties / normality
limitations
support needs
adulthood
race
gender

The future

hopes and fears
job
leaving home
relationships
1. Tell me about your self-advocacy group
   what kind of group is it?
   how long have you been going?
   what do you talk about and what has it done?
   why do you go?
   tell me about your adviser
   how important is the group?

2. What is self-advocacy?
   how important is self-advocacy?

3. Tell me about speaking up at home
   do you speak up at home?
   do you have control at home? Are you in charge of yourself at home?

4. Do you know what goes on in your family?
   are you included in family decisions / discussions / talks?
   do you feel involved or left out?

5. Tell me about housework
   do you do housework / jobs in the house? are you in charge of some things?
   do you look after anyone?

6. Tell me about the rules in your house
   who makes the rules?
   what are they?

7. Tell me about making choices at home
   do you choose what to eat?
   what to wear?
   what to watch on TV?

8. Think about a normal day. Can you tell me about the choices you make through the day?

9. Tell me about going out.
   do you? on your own?
   do you have to ask permission?
   do you have to be taken?
   do you have to say when you'll be back?

10. If you want to talk, does your mum / dad / family listen?
    what you've been doing?
    feelings?
11. When you do something well at home, is it noticed? 
   when you do something well at work / at the centre is it noticed at home? 
   do you talk about it? Are they pleased?

12. Tell me about you money. Who is in charge of it? 
   what do you spend your money on? 
   what happens about buying clothes? 
   do you save up for big things? 
   where do you keep it? 
   do you need help with money? 
   do you pay rent, bills etc?

13. What makes you an adult? 
   are you treated like an adult at home?

14. Do you have any plans for the future? 
   do you talk about jobs / leaving home / the future with your family? 
   who makes the decisions about your future?

15. Tell me about independence. 
   what do you think it is? 
   are you independent? do you want to be independent?

16. Leaving home - what keeps you at home?

17. Are families talked about in the self-advocacy group? 
   by you or anybody else

18. Is there communication between the self-advocacy groups and home? 
   like letters, phone calls, meetings with parents

19. Do you talk at home? 
   about self-advocacy / about the group

20. What do your mum / dad know? 
   about self-advocacy / about the group

21. What do your mum / dad think? 
   about self-advocacy / about the group

22. Does what your mum / dad think affect you? 
   does it make it easier or harder to speak up? 
   if they don't like you doing something, do they try and stop you?

23. Should your mum / dad know more? Why? How?

24. Does the self-advocacy group help you to speak up at home?
PARENTS - INTERVIEWS 1 & 2

receiving the news
early years
services, professionals
support networks
impact on life
care after a long time
positives / negatives
ordinariness
siblings

Daughter / son's life

story
adolescence
adulthood
race
gender
self-advocacy

The future

hopes and fears
jobs
relationships
leaving home
family links
own future
PARENTS - INTERVIEW 2 or 3

1. What do you know about self-advocacy?
   What do you know about the self-advocacy group?

2. Do you talk about it at home?

3. Is there communication between the self-advocacy group and home?

4. What do you think
   about self-advocacy?
   about the group?
   normality of self-advocacy?

5. Should / would you want to know more? How?

6. How important is the group in ...'s life?
   How important is self-advocacy in ...'s life?

7. Changes as result of self-advocacy

8. Does ... speak up at home? Does ... have control at home?

9. Is ... included in family decisions / discussions?

10. What contribution do they make to the household?
    housework
    care
    money

11. Are there house rules? Who makes them?

12. Does ... make choices at home? Take me through a typical day.

13. Does ... go out?
    transport
    permission
    on own
    time etc.

14. Money - who controls it?
    how does ... spend it?

15. Do you talk?
    what they've been doing / feelings
    listening
16. Does ... achieve things?
   is it talked about / celebrated?

17. Is ... an adult?
   is making decisions part of growing up? Difference between being a child and an adult?

18. Is ... independent?
   what is independence?
   will ... be in future?

19. Are there plans for the future? Who makes them?

20. Leaving home
   what keeps ... at home?

21. Has self-advocacy had an impact at home?
ADVISER INTERVIEW

1. Describe the self-advocacy group
   - history
   - membership - including how many live with families
   - adviser's role - conflict of interest, etc.
   - achievements

2. Qualities of that type of group
   - comparisons with other types

3. What are the kind of things that get discussed?

4. Do families get discussed?
   - what kind of things?

5. How much contact do you have with families?

6. What experiences have you had with parents and their approach to self-advocacy?

7. How much should families know - about self-advocacy?
   - about the group?
   - Why? How?

8. Do you have a policy / strategy on families?
   - attempt to help parents understand self-advocacy
   - attempt to get self-advocacy to transfer to home
   - What factors influence this?

9. Does self-advocacy translate to home?
   - do people speak up at home?
   - how do parents' attitudes affect people?

10. Is there a relationship between self-advocacy and adulthood?

11. Is there a relationship between self-advocacy and independence?

12. How 'normal' is the experience of people who speak up?
    - is there a link between people with learning difficulties speaking up and normal development in life?
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Elfrida Rathbone

