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## Gender, caring and learning disability

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**Gender, Caring and Learning Disability**

Thesis presented for the degree of Doctor of Philosophy.  
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# **Gender, Caring and Learning Disability**

## **Abstract**

The thesis explores the meaning of caring in the lives of a group of people who are labelled as dependants, adults with learning difficulties. Through biographical interviews and documentary research the author examines how care for people with learning difficulties has developed over time in one local area; and the understandings people on the receiving end have of the care offered them by families and staff.

The findings suggest that dependency is not acknowledged by the majority of people interviewed who present themselves as givers of care as much as recipients of care. The research identifies gender as an important variable in the way care and caring are understood and experienced.

The research makes a contribution to the literatures on gender and caring; family; peer and staff relationships of adults with learning difficulties; the history of learning disability; and qualitative research with marginalised groups.

## **Acknowledgements**

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## **Preface: A Note on Terminology**

The people I refer to in this thesis as people with learning difficulties have been subject to many different labels in the twentieth century. From idiots, imbeciles, feeble minded and mental deficient, they have been transformed into sub normals, mentally handicapped, learning disabled, intellectually impaired. I have chosen the term 'people with learning difficulties' as it is currently the label preferred by People First in Britain (Simons 1992, Swain 1993), and, as this is a piece of work which seeks to present people so labelled in the way they choose, it is logical to accept their choice of label.

However, the term has limitations, some conceptual and some stylistic. The conceptual limitations relate to the specificity of the term 'learning difficulties' which can be taken to mean solely difficulties in learning academic skills of reading and writing. This is the way some people interviewed for this research chose to interpret it, though my use of it is intended to encompass a broad range of difference from the norm in diverse areas such as employment, living situations, relationships. Rather than become entangled in continual terminological knots I have included in the category 'people with learning difficulties' anyone who was at any time in their lives in receipt of services specifically geared to this group, including Special Schools, Adult Training Centres, hospitals, hostels and group homes. It is not a wholly satisfactory solution, but the label is so hard to define that it seemed the only practical one.

The stylistic limitation is that 'people with learning difficulties' is a cumbersome term to use as an abstraction. Instead, where I refer in the abstract to learning difficulties I use the term 'learning disability' which recently has been favoured by Government Departments, particularly the Department of Health (Department of Health 1993). This aligns the problems faced by people with learning difficulties to those experienced by a broad range of people with disabilities, in contrast to

aligning them with people who have mental health problems, a practice reflected in the 1959 Mental Health Act which legislated for both groups.

The alignment of people with learning difficulties with disabled people creates a further terminological confusion. In this thesis I use the adjective 'disabled' to refer to physically disabled people, excluding people with learning difficulties. However, it is a distinction which is not always easy to maintain. Many people with learning difficulties are also physically disabled. Disabled writers and commentators such as Mike Oliver (1990) and Jenny Morris (1991) include people with learning difficulties in their analyses of disability, though they are rarely centre stage. So 'disabled' can include people with learning difficulties in some contexts, though I have tried to retain the distinction in my writing.

Finally, a historical note must be added. When writing of the past I have retained the terminology then in use. It would be anachronistic and misleading to replace 'mental deficiency' with 'learning disability' for example when at the time the latter term had not been coined. This is not intended to diminish the people being discussed; it does, however, recognise the power of language to define people, and to influence how they were perceived and treated at a particular time.

## Chapter 1: Introduction

*Mum, she got confused, you know. I had to do everything. I was in the kitchen in front of the stove, cooking milk or something, she'd say "Come in here, don't you dare go out there and do the milk." I couldn't do anything. I couldn't go out at weekends, anything. I just couldn't go anywhere. I had to stop in every weekend and look after her. She was a handful. (Deirdre: Interview 1992)*

In this thesis I examine how adults with learning difficulties describe and understand care and caring. Through the use of biographical interviews (Cornwell and Gearing 1989, Gearing and Dant 1990) I set out to discover how care and caring change over time, and to examine how gender influences peoples' attitudes towards care and their experiences of it. A biographical approach makes it possible to set people's individual lives against the background of developments in policy and practice during their lifetimes, and to challenge certain preconceived notions of who are carers and who are cared for people. The quotation above, taken from one of my research interview transcripts, is a reminder that people with learning difficulties are not only receivers of care, they are also, in some circumstances, care-givers.

The topic is of interest because it explores an area hitherto neglected in the literature, namely the significance of care and caring for people whose social identity implies dependence. Research on social care has tended to examine caring from the point of view of those who care for so-called dependants - older people and disabled adults - and the experiences of those who are cared for has rarely been addressed. This contrasts strongly with developments in the disability field which focus on the barriers disabled people experience in gaining access to normal patterns of living - work, human relationships, leisure activities, an adequate income. Specifically in the context of learning disability self advocacy - speaking

up for oneself - and normalisation - access to valued social roles such as paid worker, parent, citizen - have been influential in shaping, thought, policy and practice. Thus the social identity of dependent is at odds with discourses which emphasise the human rights of disabled people, and the importance of opening up opportunities to establish valued and satisfying life-styles.

Caring lies at the intersection between these two contrasting traditions of social thought. If people with learning difficulties are above all dependent on the care of others, then they are privileged to the extent that they are not expected to play economically or socially productive roles, they are people who deserve state charity; but they pay the penalty of being classified in the 'needs' rather than the 'work' group in society (Stone 1985). This results in their being stigmatised and oppressed, excluded from full participation. As Johnson puts it:

*To carry the label 'dependent' is to carry the burden of being deviant - someone who no longer enjoys a place in the mainstream of society and whose behaviour is 'abnormal' . (1993:264).*

Being constructed as a dependent person implies exclusion from full citizenship.

People with learning difficulties are not only viewed as social dependants; the caring work they do is all but invisible in the literature on learning disability. I was alerted to this in my previous research when I interviewed 'Gwen' (Walmsley 1989). Like Deirdre, quoted above, 'Gwen' had been a carer for her mother. From what Gwen said I gathered that her mother had dementia in her last years of life, and Gwen's life was stressful and restricted as a consequence. Careful reading of some research publications demonstrated that Gwen was not unusual (see for example Jones (1975) on hospital residents caring for others, and Flynn (1989) on people living in their own flats and houses), but few comment specifically on these care-giving roles and activities.

Therefore, an exploration of care and caring from the point of view of people with learning difficulties seemed important. If being a carer excludes people, particularly women, from citizenship as Lister (1990, 1992) argues, what impact does being a 'dependent' have, or a carer whose caring work goes unnoticed?

In this thesis I examine what people with learning difficulties have to say both about receiving and giving care. I seek to present their side of the picture, and to explore how far and in what ways they see themselves as dependants; and whether their personal identity includes being a carer for others.

In undertaking the research I took a particular interest in gender. This is because caring as an activity, and carer as an identity are seen as having a salience for women (Graham 1983). But, as writers like Jenny Morris (1992a) and Nasa Begum (1992) have observed, although some disabled people are also women, the experience of being a woman in a situation of dependency has been neglected in the literature on women and caring. It is therefore important to consider how significant gender is as a variable in the way people with learning difficulties understand and experience care.

In order to introduce the topic, I now outline four areas of research which helped me frame the questions to be posed, and answered, in this thesis:

- 1) Changing constructions of learning disability
- 2) The literature on social care, in particular the assumption that the world is divided into two distinct categories, carers and dependants
- 3) The influence of the literature on social care on research into learning disability
- 4) Research which involves people with learning difficulties as informants.

These are briefly discussed here before defining the research hypotheses. The first three are explored in more detail in Chapter 2 and the last in Chapter 3.

## **1 Changing Constructions of Learning Disability**

Conceptions of learning disability change over time (Schalock et al 1994), and the

type of 'care' people are seen to require reflects these changes (Wolfensberger 1975). The ongoing debate over terminology, what to call people 'who have been assessed as less intelligent than the average and whose condition is considered by expert opinion to be severe enough, or sufficiently troublesome to others, to require special identification' (Jenkins 1993:17), reflects continuing uncertainties about the nature of learning disabilities. The term 'people with learning difficulties' implies that problems can be overcome if appropriate learning opportunities and supports are available. Currently other terms are in use, such as 'mental handicap' and 'learning disability', and they are but the latest in a long series of labels applied to this particular social group - such terms include 'idiot', 'imbecile' 'feeble minded', 'moral defective', 'backward', 'subnormal', 'ESN', 'slow', 'mentally handicapped' all in use within the twentieth century alone. Wolfensberger (1975) argues that changing ideological perceptions give rise to different types of services. Medical definitions are of limited use. As Jenkins (1993) observes, only a minority of people labelled as 'people with learning difficulties' have recognised medical conditions, such as Downs Syndrome. The contested and shifting meanings of the labels attached to people who are deemed intellectually incompetent suggest that the nature of learning disability is culturally and historically specific, (Edgerton 1976) and that their status as a socially dependent group is therefore open to debate. Currently most services for people with learning difficulties are framed in terms of 'care': 'community care', 'day care', 'residential care' (see for example Brown and Benson 1992, Open University 1993). But what 'care' means in this context is unclear, for the aims of services for people with learning difficulties have changed over time, and continue to change. Care in mental deficiency colonies and hospitals meant segregation from the wider community, and having all material needs met within the institution (Ayer and Alaszewski 1984, Ryan 1987). Care in more progressive services today means offering people the support they need to live 'an

ordinary life' (Sperlinger 1992), and promoting as far as possible the independence of individuals (Corbett 1989). It is nevertheless the case that 60 per cent of adults with learning difficulties live with their families of origin (Simons 1992) and this reflects both an ideological assumption that people are best cared for in families (Bayley 1973, Hattersley et al 1987, Abbott 1990), and the relative cheapness of so-called 'informal care' (Dalley 1989, Morris 1993).

The idea that care is what people with learning difficulties need sits uneasily with discourses which emphasise peoples' rights. The construction of disabled individuals as socially dependent has been challenged, largely by disabled academics such as Finkelstein (1980) and Oliver (1990). The argument is that dependence is framed by the medical model of disability which portrays disability as an individual tragedy to be overcome by the application of social support mechanisms, and assistance to the individual to 'accept his condition' through counselling (Oliver 1993a). In place of the medical model, is proposed the 'social model', where disability is seen as a social construction, created by the failure of able bodied society to adjust to the particular needs of disabled people (French 1993).

The 'social model' has not been consistently applied to the experiences of people with learning difficulties (Walmsley 1994). Much recent debate in learning disability has been influenced by the Normalisation Principle as enunciated by Nirje (1969) and Wolfensberger (1972), Wolfensberger and Tullman (1982), Wolfensberger and Thomas (1983). This emphasises the right of people with learning difficulties to have 'culturally normative lifestyles' (Williams and Walmsley 1990:91) or socially valued roles (Wolfensberger and Thomas 1983). Wolfensberger in particular has drawn attention to the importance of deviancy-making in socially devaluing 'mentally retarded people' (Wolfensberger and Tullman 1982). This differs from the social model in that it attributes the blame for



stigmatisation on the negative value society places on certain characteristics, rather than on the barriers which exclude people from full participation in society (Chappell 1992 and forthcoming). Thus in the normalisation paradigm the duty of 'human services' becomes the reversal of societal devaluation through the creation of socially valued roles, and positive social imagery, rather than dismantling the barriers which exclude disabled people from participation in society. Little attention has been paid specifically to giving and receiving 'care' as an aspect of normalisation, though Wolfensberger has commented on the importance of traditional gender roles, arguing that a man with learning difficulties should not be encouraged to 'spend his working day at tasks which have been historically thought of as women's work' (Wolfensberger and Thomas 1983:462). It has been left to physically disabled writers, in particular Morris (1993a) to challenge the idea that 'care' is what disabled people need.

In this thesis I propose that it is not self evident that people with learning difficulties are dependants. An overview of the historical development of policy in relation to learning disability shows that constructions of this group by policy makers and researchers alike have shifted over time, and that the belief, prevalent in current research and policy, that the family should be supported to care for people with learning difficulties, is relatively recent, and is only one of several competing discourses about the nature of learning disability.

This thesis makes a distinctive contribution to the debate on the social construction of learning disability by examining the way some adults with learning difficulties construct their identities in relation to care and dependence. It explores in a local context how the ideological model of family based care as the ideal for people with learning difficulties emerged over time, and how these changes are reflected in the life experiences of the people I interviewed.

## 2 The Literature on Social Care

People with learning difficulties have been missed off the agenda by researchers into social policy and social care. Jenny Morris (1991, 1992a) and Nasa Begum (1992) have argued that feminist research on caring 'has failed to take on the reality and the interests of those groups who receive "care"' (Morris 1992b:22). In making these points they are adding their voices to others, notably Hilary Graham (1991, 1993), who have seen the literature on women and caring as being excessively grounded in the experiences of white, heterosexual, non disabled women. Morris notes that the experiences of disabled women have failed to appear on the feminist agenda (1992a:157). If this is true of disability generally, it is even more the case that the experiences of people with learning difficulties have been ignored not only by feminists, but also in the mainstream literature on social policy and social care. Neither Morris nor Begum makes specific reference to women with learning difficulties in their critiques of the literature on women and caring (Morris 1991, 1992a, 1992b, Begum 1992). No reference is made to people with learning difficulties in key social policy texts such as those by Thane (1982), Digby (1989), Williams (1989) and Conrad and Schneider (1992), nor in the now fairly extensive recent literature on citizenship (Turner 1986, Harris 1987, Hindess 1987, King 1987, Barbalet 1988, Lister 1990). Thus in mainstream research into social policy, where they are discussed at all, people with learning difficulties are cast as unquestionably dependants, recipients of care, whose specific experiences are only of interest insofar as they present problems to their 'carers'. They are seen, when noticed at all, as burdensome dependants (Walmsley 1993a). Feminists, such as Finch (1984a) and Dalley (1988) have drawn attention to the invisibility of the work women do as carers, but so far such research has not addressed the impact of gender on so-called dependants, nor has it acknowledged that people who are often seen as 'dependants' also operate in some circumstances as care givers.

Johnson (1993), in the context of old age, and Oliver (1990), in the context of disability have both argued for a re-evaluation of contemporary assumptions about the nature of dependency. Both Johnson and Oliver argue that *interdependence* is integral to the experiences of everyone living in a complex society:

*No one in a modern industrial society is completely independent for we live in a state of mutual interdependence. The dependence of disabled people, therefore, is not a feature which marks them out as different in kind from the rest of the population, but as different in degree.*

(Oliver 1990:8)

Johnson argues that to be labelled as a dependent means exclusion from the mainstream of society (1993, see p. 2 above). This aptly sums up the importance of research which challenges assumptions about the essential dependence of people with learning difficulties. The contribution made by this thesis to the debate on social care is to show that when people who are labelled as dependants are asked about their perceptions of themselves a more complex picture emerges, one which incorporates elements of care giving as well as receiving care, a personal identity which is at odds with the social identity of 'dependent'.

### **3 The Impact of Research into Social Care on Learning Disability Research.**

Although the experiences of people with learning difficulties have been largely ignored in contemporary debates on social care and social policy, there is an extensive body of research into the lives of people with learning difficulties which is influenced by the assumption that people with learning difficulties are essentially dependants. Recent examples include Morag McGrath and Gordon Grant's British study which focuses on the 'problems faced by carers of children and adults with

learning difficulties' (1993:25) and Seltzer, Wyngaarden Krauss and Tsunematsu's US study of adults with Downs Syndrome and their ageing mothers (1993) which examines the perceptions of the ageing mothers of their social supports, and the 'stress' and 'burden' of caregiving. Such studies have in common with many others two features which are of interest in the context of the thesis; firstly, the perception that adults with learning difficulties are burdensome to their families; and secondly, a lack of interest in people with learning difficulties as potential or actual givers as well as receivers of social support. The literature on the social relationships of people with learning difficulties has clearly been influenced by the literature on women and caring discussed above. For example some research into the social support networks surrounding people with learning difficulties acknowledges the importance of gender (Smith and Brown 1989, Traustadottir 1991), but the interest is in the gender of the caregiver, rather than in gender as a variable for people with learning difficulties.

In seeking the views of people with learning difficulties of their experiences of giving and receiving care, this thesis makes a contribution to the theorisation of care, dependency and interdependence which creates links with the current literature on social care, and places the experiences of people with learning difficulties in a wider context, acknowledging that they too can be care givers, and that they have characteristics such as gender, class and age which will modify their experiences of care.

#### **4 Research which Involves People with Learning Difficulties as Informants**

One of the possible reasons for the gaps in research identified above is that it is only comparatively recently that researchers have begun to ask people with learning difficulties to tell their side of the story. For many years the work of Robert Edgerton (1967), Edgerton and Bercovici (1976) and Robert Bogdan and Steven

Taylor (1976, 1982) stood out as isolated examples of studies which sought the views of people with learning difficulties. The 1980s saw a modest flowering of papers which discussed issues in interviewing people with learning difficulties (Sigelman et al 1981, Wyngaarden 1981, Flynn 1986, Atkinson 1989), but it is in the last four years that serious efforts have been made to develop research methodologies which include the views of people with learning difficulties as the major source of information, rather than one amongst a battery of approaches (for examples of such studies see Atkinson 1986, Flynn 1989). Such methodological innovations have been influenced by the development of self advocacy (Simons 1992). Notable amongst recent British research projects which give pride of place to the voices of people with learning difficulties are Atkinson and Williams (1990) edited Anthology, *Know Me As I Am, Homeward Bound* by Booth, Simons and Booth (1990), Jenkins and Aull Davies' research on adulthood (1991), Potts and Fido's (1991) oral history *A Fit Person To Be Removed*, Simon's research on Self Advocacy (1992), Booth and Booth's study of parents with learning difficulties (1994), and Atkinson's work on group reminiscence (1993 a, b and c). As the approaches and findings of these research projects become published and better known, it is likely that many of the gaps identified above will be filled.

In undertaking the research on which this thesis is based I built on and adapted the work of other researchers who have included people with learning difficulties as their principal informants.

### **The Research**

This research adds to the methodological literature which explores ways of giving people with learning difficulties a voice. Semi structured biographical interviews developed in gerontology (Cornwell and Gearing 1989, Gearing and Dant 1990) were used with people with learning difficulties to obtain a picture of their lives over time. This was supplemented by historical research which makes it possible to

view their lives in the context of changes in ideology and practice related to learning disability. This combination points to some possibilities for people with learning difficulties to act as historical commentators as well as informants about their own distinctive experiences, and this is examined in the data analysis.

There were two principal strands of field research: semi structured biographical interviews with 22 adults with learning difficulties living in the Luton area; and historical research into the development of learning disability services locally, comprising both oral history interviews and documentary research.

The research makes a distinctive contribution by presenting the perceptions people have of their lives, rather than creating a rounded and apparently 'objective' account drawing on a variety of sources. This strategy is justified because the views of people with learning difficulties have been so rarely canvassed in research on their lives to date. The role of the historical research is to set a wider context in which peoples' distinctive biographical experiences can be seen, and also to explore possibilities for combining oral and documentary sources to create a local history of learning disability.

### **The Thesis**

The thesis I propose to test in this research is that asking adults with learning difficulties to describe their experiences of care and caring will generate new perspectives on an established area of social research.

Stating a thesis at the beginning of a piece of qualitative research is in many ways a contradiction in terms. Boulton and Hammersley (1993) argue that the researcher who espouses grounded theory should generate categories through the data analysis, rather than specify them at the outset. This research is exploratory, both in terms of its content and in terms of its method. Care and caring as seen by adults with learning difficulties is a new research area; biographical research is relatively

unried with adults with learning difficulties (Booth and Booth 1994); and combining oral and documentary sources to create a local history of learning disability in the twentieth century is also entering into uncharted territory. Nevertheless, no researcher can approach her task with a completely open mind, free of any theorising (Bowles and Duelli Klein 1983), and I would acknowledge that in producing an initial research outline I set out a position which influenced the way the research was approached and structured.

Therefore it is helpful to set out a thesis whilst recognising that through the process of research new areas were opened up, and existing assumptions challenged. The thesis gives rise to a set of hypotheses. These hypotheses, derived from the literature briefly described above, are;

- that adults with learning difficulties have a valuable and valid contribution to make to research into caring
- that adults with learning difficulties have a contribution to make to the process of historical research
- that if adults with learning difficulties are asked to talk about their lives they will not identify themselves in terms of care and dependency
- that adults with learning difficulties will see themselves as caregivers as well as recipients of care
- that gender will mediate the experiences adults with learning difficulties have of care and dependency, and the way they describe these experiences
- that the social identity of people with learning difficulties is culturally and historically specific
- that the family has a central and contradictory role in relation to care and adults with learning difficulties.

These hypotheses structure the final chapter in which the findings are summarised.

### *The structure of the thesis*

The thesis is structured as follows;

Chapter 2 *Gender, Caring and Learning Disability: A Review of the Literature* begins with a historical overview of the way learning disability has been

constructed in twentieth century Britain. I then review the literature on social care, in particular research by feminists into caring, and examine recent critiques of the literature from the point of view of disabled people and older people, introducing the concept of 'interdependence' and reciprocity.

I also review research into the social relationships of people with learning difficulties which places them as dependants at the centre of a network of care givers, and examine how results of research in which people with learning difficulties speak for themselves contrasts with findings from research in which others speak for them.

Chapter 3 *Research Methodology: Rationale and Literature Review* sets out the methodological justification for the approach taken in this thesis. I consider how far self advocacy has influenced the agenda of research into learning disability, and situate qualitative research with people with learning difficulties within the broad context of research in which powerless and marginalised groups speak for themselves.

Chapter 4 *Research Method: Data Collection and Analysis* describes the research method, data collection and analysis.

Chapter 5 *Learning Disability in Luton 1946 to 1992* describes the results of the historical research in terms of provision for people with learning difficulties in the area where the interviewees live, and the changing ways they have been viewed and treated over time.

Chapter 6 *Introducing the Interviewees and their Context* introduces the interviewees and their current life circumstances, and examines dependence, independence and interdependence.

Chapter 7, *Representative Lives?* comprises the 'auto/biographies' of four of the respondents, and discusses how far their lives can be seen as representative of



people with learning difficulties of their age and gender

Chapter 8, *Care and Caring: Meanings and Experiences* examines how people talk about care, and looks at how caring relationships have changed over time.

Chapter 9 *Gender, Caring and Identity* discusses how far people integrate the social identity 'person with learning difficulties' with their personal identity, and demonstrates that their self-images appear to mirror contemporary confusion about the implications of the label

Chapter 10 *Research Findings* discusses the research findings, their significance, and implications for practice and future research.

There are five Appendices:

Appendix 1 is an alphabetical list of the interviewees.

Appendix 2 is an example of an individual's life story written as an outcome of the interviews.

Appendix 3 is a list of sources consulted in the Bedfordshire County Record Office.

Appendix 4 is a brief history of learning disability in England 1913 to 1992.

Appendix 5 contains extracts from taped interview transcripts.

After the list of References I list the publications arising from this work to date.

## **Chapter 2: Gender, Caring and Learning Disability: A Review of the Literature**

### **Introduction**

This chapter reviews the literature on caring and people with learning difficulties and examines how people with learning difficulties have been constructed as social dependants by policy makers and researchers. The argument is that the construction of people with learning difficulties as dependants renders them passive and marginal, and is at odds with discourses which emphasise rights, citizenship and choice. Hence the significance of caring: the relations people have to caring are central to the way they are seen, and treated. As dependants, they are passive; as carers they have the potential to be social agents, actors as well as acted upon. This chapter touches on the way certain research methodologies construct people as dependants, and others which challenge that construction. These issues are discussed in more depth in Chapter 3.

People with learning difficulties are seen as dependants in need of care in policy terms (HMSO 1971, Jones 1972, HMSO 1989), in the literature on caring within the family (Abbott and Sapsford 1987, Wilkin 1979, Jackaman 1991, Grant 1993), and in the training of professionals (Middleton 1988, Hattersley et al 1987, for example). The force of these perceptions is demonstrated by the ubiquitous use of the term carer for people who live or work with people with learning difficulties (Walsh and Conliffe undated, Fox 1992, McGrath and Grant 1993), and the designation of services and people as 'care categories' (Baker and Urqhart 1987), 'care management' (Renshaw 1987, Richardson 1991) or community care (HMSO 1989, Dalley 1989, Open University 1993).

These assumptions co-exist uneasily with perspectives which emphasise citizenship (Walmsley 1991a, Rioux 1992), choice-making (Hart 1992, Cookson 1992) and self advocacy (Williams and Schoultz 1982, Gosling 1992, Simons 1992, Sutcliffe

and Simons 1993). There are few points of contact between the two sets of debates, though some self advocates have taken issue with the language of community care; 'we are weary of the term 'community care' because it implies we need caring for rather than supporting us to live our lives in the community' (Northamptonshire People First 1993).

In this literature review I explore how people with learning difficulties have come to be viewed as a quintessentially dependent group, and show that this idea is open to debate on several grounds including critiques of the meanings of care and dependency, and the views people with learning difficulties have of their personal identity and social roles. I show that social scientists have long assumed the dependent status of people with learning difficulties in undertaking research into caring. If this is challenged, if people are seen as both carers and cared for, then they too can be seen as actors, not just the passive recipients of the care of others. Hence the importance of examining care and caring as experienced by people with learning difficulties.

The Chapter is divided into four sections. In Section 1 I examine how people with learning difficulties have over time come to be seen as people in need of care, in particular family care. In Section 2 I review how debates on care as a social policy issue have influenced the agendas of learning disability research. In Section 3 I summarise the findings of research into the social relationships of people with learning difficulties, including relationships with family, friends and paid supporters, and the significance of gender; and conclude with Section 4, Personal Identity, Care and Dependency in which I examine the way people with learning difficulties describe themselves and their relationships.

### **Section 1      Care, dependency and learning disability: the construction of a dependent group**

In this Section changes in the way learning disability has been viewed over time are

examined to show how they have come to be viewed as a dependent group.

In the early twentieth century the 'feeble minded' were at the centre of debates about social problem groups (Jones 1986, McNicol 1987), largely as a result of the introduction of compulsory education which brought them to public attention (Ayer and Alaszewski 1984, Hurt 1989), and of eugenically inspired moral panics about the degeneration of the 'race' (Fernald 1919, Simmonds 1978, Barker 1983). In the Report of the Royal Commission on the Care and Control of the Feeble Minded (1908), and in the Parliamentary debates prior to the passage of the Mental Deficiency Act (1913) women were singled out as being particularly threatening: 'case after case is cited of feeble minded women bearing large numbers of illegitimate feeble minded children who, in turn, bred more feeble minded children' (Simmonds 1978:394). The 1913 Act itself singled out women who were in receipt of poor relief when pregnant or at the time of giving birth to an illegitimate child as 'subject to be dealt with' (Simmonds 1978:399), and there is evidence that women were targeted more systematically and institutionalised for longer than men by Local Authorities in the inter war years (Thomson 1992). Both Simmonds (1978) and Thomson (1992) argue that the Act of 1913 and its subsequent implementation was motivated both by humanitarian concern for the welfare of 'mental defectives', and by fear of their potential to overwhelm the 'fit'; that is a mixture of care and control.

The Act of 1913 legitimised the medical basis of diagnosis and ascertainment of mental deficiency: 'It was accepted that a properly qualified specialist, in England a medical practitioner, had sufficient knowledge and skill to identify correctly the objective signs of mental deficiency' (Alaszewski and Ong 1991:13), and this 'medical model' remained dominant in the study of learning disability (Wolfensberger 1975:5, Williams 1993), a model in which people are deemed to require medical care. The incorporation of mental deficiency services into the

National Health Service in 1946 reinforced the dominance of the medical profession, though few patients actually required medical treatment (Ayer and Alaszewski 1984).

Whilst mental deficiency was central to debates within social policy in the early part of this century, after the 1930s it became a physically and intellectually isolated specialism dominated by psychiatry, psychology and education (Williams 1993). The passivity and neediness of people with learning difficulties went unquestioned (Jones 1972); they were seen as people who needed physical care, and control, either within the family or in institutions on the basis of an unchanging and unchangeable individualised pathology (see for example Burt 1952, Lyons and Heaton Ward 1955, Pritchard 1963).

Alaszewski and Nio Ong trace the impact of sociological ideas on the study of learning disability, and describe how studies of deviance began to challenge assumptions of hereditary and medical causes of mental handicap (Dexter 1964, Mercer 1970, Wolfensberger 1972), the argument being that society created the deviant behaviour rather than vice versa (Alaszewski and Ong 1991:14 -15). It is possible to trace from these early critiques subtle changes in policy rhetoric and, more slowly, in practice which reflect a growing recognition that people with learning difficulties have rights to use mainstream services and enjoy normal patterns of life (HMSO 1971, Warnock Committee 1978, Jay Committee 1979), accompanied by studies critical of institutional practices (Morris 1969, McCormack 1979) which followed the hospital scandals of the 1960s (Donges 1984). Such studies portrayed people as helpless victims of inhuman practices, and emphasised the importance of caring family-type environments (see for example McCormack 1979:61-2).

The 1950s and 1960s, therefore, saw a move away from the assumptions that had informed the 1913 Act, that mental defect was inherited, and that people with

learning difficulties required care and control in institutions (Ayer and Alaszewski 1984), to a perception of them as 'a group of unfortunate individuals requiring special support, help and protection' (Ayer and Alaszewski 1984:30) and an interest in family based care (Alaszewski and Ong 1991:21-22). The change in philosophy was encapsulated in the 1954 Royal Commission and the subsequent 1959 Mental Health Act (Jones 1972, Clarke and Clarke 1978a), which superseded the Mental Deficiency Act, though in practice the numbers of people in hospital continued to expand until the late 60s (Stainton 1992a).

The shift in philosophy coincided with mobilisation of the parents' voice via self help organisations, in particular the National Society for Parents of Backward Children (later MENCAP) (Shennan 1980, Stainton 1992b). Bayley (1973) articulated the growing interest in support for family care in the community 'the community caring at the small scale face to face level is and must be the basis on which all services depend' (1973:12). Abbott comments: 'Caring for a mentally handicapped child may seem to be so obviously the responsibility of the parents that it seems strange to question this' but points out that only 30 years ago parents were advised to put their children in hospital (1990:4) The shifts, from medical to humanitarian conceptions and from institutional to community care, however, did not challenge the essential perceptions of people with learning difficulties as dependants, though Mercer's (1973) critique might have led to the conclusion that dependency was itself socially created, rather than a property of the individuals themselves. The nature of the care offered to people changed, albeit slowly, with a growing emphasis on support for families, but that they were in need of care went unchallenged.

Explanations of mental handicap or mental retardation inspired by ideas of deviance have continued to dominate research, policy and practice since the 1970s under the banner of normalisation (Emerson 1992). Normalisation has influenced

thinking and practice in learning disability via PASS and PASSING training for professionals (Lindley and Wainwright 1992) and has been used as a tool for evaluating the quality of services (O'Brien and Lyle 1987, Felce and Toogood 1988). It is debatable how far normalisation challenges the notion of dependency. It fails to identify those barriers to full participation in society, such as poverty and exclusion from the labour market, which have been noted by several disabled academics (Oliver 1990, Morris 1991). It has been described as something adopted 'largely by professionals and service providers, rather than disabled people themselves' (Whitehead 1992:57), and Chappell argues that because victim status is integral to deviancy theory it may actually serve the interests of those who provide services better than those who receive them (1992). However, normalisation and its refinement, social role valorisation (Wolfensberger and Tullman 1983), emphasise that people with learning difficulties need to be seen as givers as well as takers from their communities. The third of O'Brien and Lyle's five accomplishments (1987) is 'contribution to the lives of others', for example.

Perhaps more significantly, critiques of normalisation informed by Christian humanism (Robinson 1989, Bayley 1991), feminism (Smith and Brown 1989, Brown and Smith 1992a) and anti racism (Ferns 1992) have demonstrated the imprecision of the concept of 'normal'. Particularly in terms of gender, critics have shown that adherence to the prevailing norms of society (Wolfensberger 1972) reproduces inequality based on gender stereotyping (Brown and Smith 1992a, Williams 1992). Thus women may be pushed into caring roles because they are seen as normal for women (see below, Sections 2 and 4).

The most fundamental challenges to normalisation have been made by disabled researchers. Analyses influenced by the so called social model of disability, in which 'disability is viewed as a problem located within society rather than with individuals who happen to have impairments' (French 1993:17) define dependency

as a social construction (Oliver 1990). Morris writes 'Both old people and those with physical, sensory and intellectual impairments are measured against normality and found wanting' (1993a:35). Rae argues that gender stereotyping compounds the oppression inherent in disability. Because women receive less domestic support than men, and are socialised into caring for others 'we are perceived as women who are part and parcel of the gender society has identified as natural carers - women' (Rae 1993:431).

Though the application of the social model is less well developed in relation to learning disability (Williams 1993, Walmsley 1994), and normalisation remains the major philosophy informing practice, the critiques developed by disabled people can apply equally to people with learning difficulties, as I show in Sections 2 and 3.

In this section I have shown how people with learning difficulties have been constructed as dependent people, in need of care, and that, despite theoretical perspectives, such as those developed by Mercer (1970, 1973) and Oliver (1990), which have the potential to challenge such constructions, the dominant view is of them as a dependent group.

## **Section 2: Caring and Social Policy: Concepts and Critiques**

In this Section I develop the discussion about care and dependency in more detail. I draw on social policy research into informal care within the family, perspectives from gerontology, disability and feminism, and conclude with a discussion of the meaning of the term care itself. The argument is that much social research into care and caring is predicated upon the uncritical construction of people with learning difficulties as dependants, with a consequent 'undermining of their humanity' (Morris 1993a:44).

Interest in learning disability has been largely confined to specialists. Influential texts on the history of social policy such as Thane 1982, Cohen and Scull 1983,



Digby 1989 and Williams 1989 neglected learning disability, though Williams subsequently acknowledged that this was an unjustifiable omission (1993). Oliver (1990) only obliquely incorporates people with learning disability into his sociological analysis of disability.

However, research into learning disability has been influenced by trends in social policy, particularly by social network research and feminist research into caring. As this has framed many of the assumptions about dependency in learning disability research it will be used here as a 'case study' of the way the literature has developed.

### *Feminist research into caring*

Research interest in informal caring burgeoned in the 1970s and 1980s, largely as a result of Government commitment to community care which appeared to assume the availability of unpaid care (Dalley 1989, Parker 1993); and the development of feminist analyses which argued that the 'golden age' myth of families supporting their own kin (Young and Willmott 1957, Townsend 1962, 1963) was based on an uncritical assumption that women did the caring (Land 1978, Finch and Groves 1980): 'Carers, perhaps for the first time, were on the agenda of what our cultural climate names as important' (Keith 1992:168).

Simultaneously, social networks, and their capacity to interweave formal and informal networks of support (Bayley 1973, Abrams 1977) became a subject of interest for policy and practice (Barclay Report 1982, Bayley and Tennant 1984).

The two strands, feminist analyses of social relationships and social networks research, began to fuse in the work of the Equal Opportunities Commission (1980, 1982), Nissel and Bonnerjea (1982) and Ungerson (1983), and the findings tended to support the thesis originally put forward by Land (1978), Wilson (1977) and Finch and Groves (1980) that 'the welfare state was built on the unpaid and low

paid work of women' (Williams 1989:6).

Theorisation of the significance of caring to women found its most influential spokesperson in Hilary Graham (1983) who explored the meaning of care to women as both love and labour, and argued that it both confined women to the private sphere of the family and gave them access to public roles as teachers, nurses, secretaries etc. She noted that dependency was contradictory for women; 'Thus for many women being a dependent is synonymous not with receiving care but with giving it'. Graham's public/private dichotomy was developed by other feminists, some of whom argued that women's caring responsibilities deny them full participation in society as citizens (Lister 1990, Ungerson 1993).

The desire to liberate women from the burdens of care for children, older people and adult disabled offspring led to calls for a reversal of deinstitutionalisation on the grounds that it exploited female carers (McIntosh 1981, Finch 1984a, Dalley 1988); and demands for a wage for carers, to elevate the status of caring in society (Ungerson 1990).

Feminist research into caring began with an interest in care for older relatives (EOC 1980, 1982, Nissel and Bonnerjea 1982), but rapidly expanded to include carers for children with disabilities (Baldwin and Glendinning 1983, Briggs and Oliver 1985, Abbott and Sapsford 1987). This research is characterised by a particular set of assumptions; that caring is burdensome and stressful (Pahl and Quine 1987, Whittick 1988, 1989), that caring limits the opportunities women caregivers have for social activity and employment (Ayer and Alaszewski 1984, Brody et al 1987, Miller and Montgomery 1990), and that caregivers have particular needs to which services should respond (McConachie 1986, McGrath and Grant 1993). Morris writes 'the public representation of informal carers has tended to take the need for informal care for granted, and addressed the interests of those who fulfil the role thereby created' (1993a:36). The findings in relation to learning disability are

summarised below in Section 3, but it is important to note how they augment assumptions that people with learning difficulties are a dependent group.

### *Critiques of feminist research into caring*

The limitations of feminist research into caring and social networks have been noted from a number of angles. These are described here as such critiques can also challenge the construction of people with learning difficulties as a 'dependent group'.

Gerontologists have challenged the concept of dependency, and propose interdependence and reciprocity as alternatives. Alan Walker described dependency as 'primarily a social relationship resting upon the exercise of power' (1982:127) and argued that the way informal care was structured created dependency for both caregiver and recipient, a common feature for both being financial dependency based on exclusion from the labour market (1982).

Dant describes dependency as 'a form of relationship characterised by an unequal distribution of power' (1988:171), and helpfully distinguishes two ways in which it is used in the literature on gerontology, the first, 'structured dependency' being to describe and criticise a relationship between old people and the state that is determined by social policy, and the second, 'dependency scales', to categorise elderly people for research and planning purposes. He concludes that neither version of the concept is adequate, and that 'Dependency is a characteristic of relationships, of structures that emerge in a process of unequal relations between people' (1988:183). Wilkin also sees dependency not as an individual characteristic, but an attribute of a social relationship (1990:20).

Other researchers have identified reciprocity between the generations. The degree to which older people were both givers and receivers of care was a feature of Wenger's research (1984), and Johnson argues 'it is evident that we live in an

interdependent world. There is no one who in any proper sense is "independent". Sixsmith (1986) found that older people valued physical independence, autonomy (capacity for self direction) and reciprocity or interdependence (not being under an obligation to anyone). Such research suggests that 'Dependence and independence should not be seen as dichotomies but as part of a spectrum which involves interdependence and reciprocity' (Arber and Evandrou 1993:19).

The significance of these arguments is more than semantic. As Hockey and James argue in their study of older people, being labelled as a dependent person is tantamount to being deprived of 'autonomy, self determination and choice' (1993:3), a denial of full adulthood. They identify care as the means by which people are excluded from full participation in social life: 'Ideology sustains relations of power through a transformative process which represents social reality in such a way as to highlight those aspects which serve the interests of a dominant group - able bodied adults' (1993:37). In western cultures, say Hockey and James, the child is the dominant model of dependency, hence the infantilisation of older people and disabled people, a practice noted in research into mental handicap hospitals (Jones 1975, Alaszewski 1986, Ryan 1987) and in the denial of sexuality and adulthood to people with learning difficulties (Jenkins 1989, Brown 1994).

These debates reappear in critiques developed by disabled people, which also highlight gender and denial of citizenship rights to so-called dependants. Oliver (1990, 1993a) shares Johnson's view that dependence is a matter of degree, not a characteristic which sets people apart. Disabled feminists have addressed the limitations of feminist research into caring, taking issue with the distinction drawn between 'women and dependent people' (Dalley 1988 quoted by Morris 1992:60) as if they are two groups whose interests are in conflict. Morris also challenges the failure of feminists to 'take on the subjective reality of disabled people' (1993b:58), and asks them to ally themselves with disabled women, rather than define them as

'other'. Nasa Begum discusses the dilemmas faced by disabled women vis a vis caring:

*Occupying a position in 'no women's' land' may either a) push disabled women into choosing very traditional feminine roles to aspire to notions of 'normality'; or b) to select non traditional female roles as a process of default rather than personal choice.*

(1992:74-5)

She pleads for feminists to include 'the dual oppression of sexism and handicapism' in their analyses (1992:70). Keith argues that feminist research on caring has unhelpfully polarised disabled people and their carers, and ignored the interests of those cared for (1992), and Lloyd summarises: 'The force of the feminist argument has been provided through the construction of the disabled person as a burden' (1992:215).

Gillian Parker integrates the perspectives of feminist researchers into caring, and those of disabled women, and acknowledges that 'The way in which dependence is constructed in the feminist debate ... rarely sees that the 'dependent person' may be giving as well as receiving help and support' (1993:252). This links with the arguments in gerontology I referred to above which see dependency very much as an attribute of social relationships in which the 'dependent person' has agency, and is able to reciprocate the care of others in various ways (Dant 1988, Wilkin 1990).

Graham (1991, 1993) says that feminists have assumed the norms of white heterosexual family life in constructing their research questions, and have failed to recognise that these norms may not apply to lesbians, Black women and working class women for whom caring 'can also be experienced as a way of resisting the divisions of class, "race" and sexuality which have worked to separate women from those they care about' (1993:128), though Graham still focuses on carers rather than 'dependants'.

The methodological limitations of feminist research into caring in the home have been demonstrated by Arber and Gilbert (1989) whose statistically based research revealed that the extent of mens' caring was overlooked, whilst Morris is critical of the absence of the voices of older and disabled people in the feminist literature (1993a: Ch. 3). Parker and Lawton comment that 'much research and writing has been based on relatively small scale, often qualitative approaches' (1994:4).

Thus, feminist research into informal home based care has been subjected to criticism from a number of quarters, and both its methodological and ideological bases have been questioned. In particular, it is argued, feminist researchers have unwittingly shored up the exploitation of so called informal carers by encouraging services which continue to facilitate their care- giving, rather than support demands for an end to the poverty and discrimination experienced by older and disabled people (Morris 1993a:49). Aronson echoes this when she says the research focus on caregiver stress was instrumental '(it) has tended to feed policy assumptions and preoccupations which aim to shore up informal care and facilitate the adjustment and coping of caregivers' (1990:62).

One of the grounds for questioning the assumptions of such research is in the meaning of caring itself and this is discussed next.

#### *Caring: activity or relationship?*

Care and caring are concepts which exist in everyday, political and academic discourse. Feminist research into caring has adopted rather a limited definition of 'caring' ; 'the concept of care has not been seen as problematic until very recently' (Thomas 1993:649). Graham concludes her review of the feminist literature by suggesting 'the need for a broader understanding of 'care' and 'caring' ..(to) take account of women's experiences of receiving care within families as well as their experience of giving it' (1993:131), and characterises much research as assuming care to mean 'unpaid reproductive work done by relatives for and in their families'

(1991:65).

Central to these discussions have been the dimensions of caring as labour or caring as 'feeling states' (Thomas 1993); and the related issue of superiority of informal (unpaid) care. These will be discussed in turn.

Thomas (1993) identifies two conceptualisations of care, that of Graham (1983) and Parker (1981). Graham sees the gender of the carer and the familial context in which she operates as primary: 'Caring tends to be associated not only with women, but with those private places where intimate relationships with women are found' (1983:16). This idea of caring as women's work within the family has underpinned many empirical studies (Ungerson 1987, Lewis and Meredith 1988). Parker sought to generalise about care using the social identity of the care recipient as the leading edge (Thomas 1993:655). He distinguished caring for from caring about, and proposed that caring for should be replaced by the word 'tending', implying physical tasks (Parker 1981). These distinctions have been developed by others. Waerness (1984) takes issue with what she sees as the obsession in British research with the formal/informal care split, and offers a redefinition of care which cuts across the boundaries and includes care - giving work, servicing of superiors, and helping, paid or unpaid. Parker and Lawton (1990a and b) propose a distinction between 'helping' and 'caring' where helping is defined as practical help from friends, neighbours and relatives who are not co-resident over long periods, and have since further refined this as a set of caring 'tasks' - personal care, physical care, paperwork, practical, keeping company, taking out, giving medicine and keeping occupied - which are indicative of the degree of involvement the carer has, and are linked to the care/help distinction (1994:12).

The idea that care is fundamentally (and preferably?) informal unpaid care within the family appears to have influenced the way care is conceptualised in paid caring relationships. Atkinson discusses the social worker as friend, and notes its

drawbacks as well as its advantages (1989b:70-71) whilst Brechin and Swain (1987), Middleton (1988) and O'Rourke (1992) are less equivocal, arguing that paid carers need to build relationships with their clients which are expressive of caring about. James (1989) talks of 'emotional labour' common to both paid and unpaid carers.

In terms of learning disability the preference for informal unpaid care over paid care has meant that the ideal is to support 'familial' models of care wherever possible - 'the most positive environment for mentally handicapped people is to live in their parental home.' (Hattersley et al 1987:99). Where this is not possible it is argued that a family environment should be reproduced: 'When a handicapped person has to leave his family home ... the substitute home should be as home like as possible' (HMSO 1971). The desirability of recreating 'family like' homes and hostels, where there was no family, was reiterated as recently as the Griffiths Report on community care (Dalley 1989).

All these discussions define care as a commodity which is bought, given or received, yet incorporates elements of altruism and affection. Qureshi and Walker's definition 'care comprises a social relationship as well as a physical task' (1989:6) offers a way out of the often false dichotomy between caregivers and dependants, because it suggests that people can be both givers and receivers of care in different relationships, and their definition can incorporate the experiences of those who are most often seen as 'dependants'. This definition sits more comfortably with those analyses in gerontology which see dependence as a characteristic of relationships, rather than a property of the individual (Dant 1988, Wilkin 1990).

It is important to note that whilst researchers describe family members who support older and disabled relatives as 'carers', carers themselves reject the sharp carer/cared for division characteristic of the literature: 'Many carers do not recognise themselves as such, instead regarding their actions as an extension of family or



personal relations' (Twigg et al 1990:3). This point is also made by Morris who argues in addition that disabled people prefer the term 'support' to care as it implies a more equal relationship (Morris 1993a).

These extensive discussions on the meaning of care have failed to recognise that care can also be a means of controlling and defining dependent groups (Hockey and James 1993). The familial ideology not only opens women carers to exploitation and exclusion, as Graham (1983) and Lister (1990) have argued, it also has the function of infantilising care recipients, even when adult - 'lack of autonomy and unreciprocated dependence on others brings a debasement of status' (Murphy 1987:72). The use of family-type models of care as a means of controlling people with learning difficulties is identified by Rafter (1983) who argues that women's reformatories in early 20th century New York had the function of 'Chastising the Unchaste' under the guise of 'rescue and reform' in 'family units'. This dimension of care as control has been little explored in the feminist debate on caring, or in relation to learning disability. This appears to be another instance of the marginality of people with learning difficulties in the broader social policy literature. For example Ingleby (1983) and Scull (1983) identify the role of professionals in maintaining social order through designating people as requiring medical care because of mental illness, but do not explore the possibility that the label 'learning difficulty' may have a similar function, and as Shakespeare (1994) points out, Conrad and Schneider (1992) unaccountably fail to discuss disability in their classic 'Deviance and Medicalization'.

The assumptions that family care is superior to paid care, and that care is unpaid health related work within families has been influential in the way research into learning disability has been conducted. Though interest in informal care in the home originated in the context of care for older people, the concepts and methodological approaches were rapidly applied to learning disability. The

critiques of this body of research demonstrate that it was a product of its time, that it incorporated a set of assumptions about what constituted care and who constituted dependent groups, and that, in its exclusive interest in caregivers, it had the effect of objectifying people with learning difficulties as burdensome recipients of the care labour of others. Ideas such as interdependence and reciprocity have been largely confined to gerontology, and have yet to be applied to relationships of people with learning difficulties. The influence the assumptions about family care inherent in the feminist and social network literature have had on research into learning disability is discussed in more detail in the next Section.

### **Section 3      Social relationships of people with learning difficulties: research findings**

Research into the social relationships of people with learning difficulties is much influenced by the body of research into informal care described above. Where researchers have looked at the views of parents or staff, the findings have tended to confirm the concept of people as burdensome dependants. This is especially true of work on the family, where the idea of supporting family care has been a prime motivator. The services support the family, and the family cares for the person with learning difficulties. This perception of people as burdensome is less evident in research where relationships with staff or others with learning difficulties are examined; though in these contexts there has been more interest in support needs than in peoples' roles as givers of care. Until recently the impact of gender on peoples' relationships has been neglected, though there is now a growing body of research which shows that women with learning difficulties may be more open to exploitation and abuse than men, and are less likely to be offered opportunities for activities outside the immediate home or service environment.

I begin the section with a discussion of family relationships; then examine relationships with staff and between people with learning difficulties. Finally I

discuss the impact of gender and sexuality.

### *Families*

I discussed in Section 1 how interest in the family as the major site of care for people with learning difficulties dates from the 1954 Royal Commission which 'emphasised the role of social workers as supporters of the family rather than controllers or supervisors' (Ayer and Alaszewski 1984:25). The message was reinforced in the 1971 White Paper *Better Services for the Mentally Handicapped* and the Jay Report 1979 (Ayer and Alaszewski 1984:17-19).

This policy interest has influenced much research into family relationships, and can be seen in the interest taken in the views of parents, particularly mothers. Wilkin (1979), Baldwin and Glendinning (1983), Ayer and Alaszewski (1984) & Abbott and Sapsford (1987) interviewed parents of young children and found that they were burdened by the care requirements of their children, and that services were inadequate: 'Services should be designed around the needs and perceptions of mothers not those of professionals' (Ayer and Alaszewski 1984:235): 'Mothers of mentally handicapped children are expected to take on an additional burden' (Abbott and Sapsford 1987:76): 'The burden goes on, moreover, potentially for ever' (ibid.:74). Other research was directed at helping parents make the best of their situation and their children. Whelan and Speake (1979) set out to assist parents in coping, whilst McConachie (1986) examined how to encourage parents to be actively involved in teaching and stimulation of their children.

Whilst some research into the experiences of families with young children indicate relatively few differences from 'normal' families (see Byrne, Cunningham and Sloper 1988), there is a general consensus that adolescence and early adulthood emphasise the differences between young people with learning difficulties and others (see Hutchinson and Tennyson 1986, Schulman and Rubinroit 1987, Horobin and May 1988). Buckley and Sacks found that 'The majority of teenagers are

warm, happy, cheerful and much loved members of their families' (1987:138), but that most were 'socially isolated with few real friends or social activities outside school .. most were very dependent on their families for their social lives' (1987:138). The absence of opportunities to undergo 'normal transitions' (Wallace 1987) from home to independent living, school to college or work, and developing opposite sex relationships has been the subject of much scrutiny (Thomson et al 1992, Frank et al 1992).

Family relationships in adulthood have been less highlighted. There has been a tendency for researchers to assume that the burdens of child rearing continue into adulthood, described as 'a constant burden' (Voysey 1985). 'Issues relating to the lifestyles of older parents of adults with disabilities have, until recently, been treated as marginal research concerns' (Todd and Shearn 1992:1). The person with learning difficulties is cast as the eternal child (Wolfensberger 1975), and the family life cycle is assumed to be arrested (Farber 1968:158). This model appears to inform the longitudinal studies into caregivers' experiences carried out by Seltzer, Wyngaarden Kraus and Tsunematsu (1992), Grant (1993), McGrath and Grant (1993) and Walsh, Conliffe and Birkbeck (1993) though there is some acknowledgement that had people with learning difficulties been asked they might have supplied different answers (Wyngaarden et al 1992:432).

The 'eternal child' model also dominates discussion of the ending of family co-residence. Parents' fears for their children's' futures have been highlighted by Richardson and Ritchie (1986) on 'letting go', and Sanctuary (1984) on parents' anxieties about what will happen after their death.

Research which taps the views of people with learning difficulties, rather than caregivers, gives a different picture. Flynn and Saleem (1986) reported that many adults wanted to leave home. Cattermole et al found that 'Parents' concern for their childrens' safety resulted in a high degree of over protection' (1988a:51) which

restricted personal autonomy and social contacts, whilst my own research indicated that younger adults aspired to 'independent living' though may not have been aware of its implications (Walmsley 1991b). Aull Davies and Jenkins discuss the extent to which parents restrict the opportunities their sons and daughters have for sexual relationships and note 'Parents are reluctant to condone, much less to foster, the growth of more serious relationships with boyfriends or girlfriends' (1994:7), though the young people with learning difficulties they interviewed often aspired to such relationships.

Whatever the research perspective and methodology there is little in the literature which examines family interdependence or reciprocity, though several authors have mentioned it in passing: for example one mother told an interviewer 'Actually I needed Martin more to be honest. I only realised it later. I could see that I needed Martin more than he needed me' (Richardson 1989:9). In reporting his social network research Grant observed '(the needs of older parents) were so enmeshed with the needs of their son or daughter that interdependence and mutual helping .. was more the norm, the person with a mental handicap being as much a giver as a recipient of care' (1993:47-49). Todd and Shearn, whose research is into family relationships between parents and their adult sons and daughters, note the gaps in the literature 'Details of how recipients of care in family settings manage relatives is missing' (1992:1). One man in Flynn's research population told her 'I gave up my job to look after my father ... Stopped to look after dad. I do full time housework here now, I do decorating, I do the lot' (1989:28).

Research into family relationships in adulthood, therefore, appears to be polarised methodologically between studies which seek the views of care-givers, primarily mothers, whose findings tend to emphasise practice implications for support to the supporters, and those which seek the views of adults themselves which suggest that leaving the parental home is a goal for many. It is hard to escape the view that such

polarisation reflects ambivalent attitudes to the adulthood of people with learning difficulties (Walmsley 1989, Jenkins 1989, Baker 1991), and the interest in the way families manage is in part the product of government imperatives to use cheap family care rather than support independent living (Morris 1993a: Ch. 3). Thus both ideology and policy become powerful forces to maintain people with learning difficulties as dependants within the family, and research has, wittingly or unwittingly, contributed to this.

### *Relationships with staff*

Research into relationships with staff is less dominated by the debate on informal care, though researchers still tend to look for peoples' support needs. For example, Atkinson describes three categories of relationships for a population of hospital leavers: formal supporters - paid professionals; informal supporters - relatives and 'handicapped friends'; and 'benefactors', 'people without handicaps' who could be called on for help (1986:85). All three categories imply that people were recipients of the help and support of others, rather than helpers or supporters themselves.

Staff - formal supporters in Atkinson's typology - have been seen as important in three respects. Firstly they can offer a model of relationships which are trustworthy (Richardson and Ritchie 1989); secondly they are a potential and actual source of other relationships through their own family and friends (Firth 1986, Specht and Nagy 1986); thirdly they can be seen as friends in their own right (Atkinson 1989). This is reiterated in some personal testimonies. One young woman interviewed by Cattermole described her key worker as 'like a sister to me' (Cattermole et al 1988a). Simons (1992) found that the self advocates he interviewed valued relationships with staff which were reciprocal, companionable, and humorous, reinforcing the idea that staff are often seen as friends.

However, staff have also been agents of control, as Ryan describes, 'it is all too easy to see hospital life in terms of the 'management' of patients' (1987:51), and

this finding is reiterated by Jones (1975) and Alaszewski (1986). Brown argues that present day services have the role of containing sexual activity: 'One implicit responsibility which parents expect services to discharge is the protection of their son or daughter from both sexual expression and sexual abuse or exploitation (1994:130). This suggests that there is an inherent contradiction in framing relationships between staff and people with learning difficulties as primarily reciprocal, and supportive.

### *Relationships with non disabled people*

Within the normalisation paradigm relationships with people who are not disabled and who are not paid to be with people with learning difficulties are highly valued (Atkinson and Williams P 1990). Such relationships have been the focus of formal schemes to foster them such as Citizen Advocacy (Wolfensberger and Zauha 1973, Simons 1993). The emphasis is on the role non disabled friends can play in fostering community integration and presence (Simons 1993). In this framework the assumption is that the non disabled person has more to offer than the person with learning difficulties. Atkinson (1986) conflates all relationships with people who neither have learning difficulties, nor are paid, as benefactors. In using this term she follows Edgerton's argument that after deinstitutionalisation people sought a competent person to support them and help them 'pass' as normal, to counteract their stigmatised status (1967), a further indication that non-handicapped friends were particularly valued. However, the term 'benefactor' underlines peoples' dependency, and implies that genuine reciprocal relationships with non handicapped people are unlikely. Edgerton's later research (1989) plays down the importance of benefactors, and it is possible that such a role is valuable immediately after discharge from hospital, but thereafter people become more self reliant.

In his research into Citizen Advocacy Simons found that a great deal could be

achieved by Citizen Advocates in extending people's networks and fighting for their rights, but when it came to reciprocity the Citizen Advocates had some reservations. One said 'She's pleased to see me and she matters to me. But I also feel she is a responsibility and she doesn't feel that way about me.' (1993:98); and another told him 'At the start I was told to see him as a friend but it was very hard.' (Simons 1993:101).

Overall, the research into these relationships portrays people with learning difficulties as potential beneficiaries; researchers have found it hard to demonstrate reciprocity.

### *Relationships between people with learning difficulties*

Research into relationships with other people with learning difficulties is not informed by the caring/ dependence axis. Instead, it is seen as an indicator of quality of life (Atkinson and Ward 1987). Such relationships fall into three major areas: friendships; intimate relationships; and relationships with other service users.

Most research indicates that friendships, other than those with family friends, are almost exclusively with other people with learning difficulties (Firth and Rapley 1989, Atkinson and Williams P 1990), and failure to establish friendships with non-handicapped people is cited by Atkinson (1986:87) as a matter of regret. However, Richardson and Ritchie recognise that peer relationships are important, and argue that ways should be found to foster them (1989).

Richardson and Ritchie (1989) identify three functions of close relationships - intimacy, company and practical help - and summarise thus: 'While people generally had an appropriate amount of practical help, a sense of rapport or intimacy with another person was often missing. Company fell somewhere in between' (p. 24). The person is not seen as a giver of support, though in passing they mention that people also wanted 'to give others help, company,



encouragement and someone to talk to’.

Some other research shows that people living alone were often quite isolated (Atkinson 1986, Donegan and Potts 1986), though some were able to maintain relationships with people known previously (Flynn 1989).

Overall, friendships between people with learning difficulties is a little researched area. Chappell attributes this to the influence of normalisation which discourages socialising with other ‘devalued’ individuals in favour of integration with non handicapped people (1992). This omission means that peoples’ roles as caregivers to one another have been largely neglected; though Brown and Smith make an interesting point in relation to gender: that women in group homes ‘assume domestic roles for men with whom they are not intimate and with whom they have not chosen to live’ (1992, quoted in Brown 1994:132).

Some researchers have noted in passing that some people with learning difficulties are ‘carers’ to other service users or family members. McCormack quotes a woman in charge of a group home: ‘The more able help the less able and enjoy doing so.. girls in particular, denied maternity, long to look after people, almost like being a nurse’ (1979:81). Jones describes a hospital resident who ‘mothered’ other patients; ‘(She) took them to the toilet or bathroom .. if any .. were unhappy she spent hours comforting them’ (1975). It is a matter of interest that although such instances are far from unusual - patients in mental handicap hospitals were expected to perform caring tasks for less able inmates (Potts and Fido 1991, Thomson 1992) - such activities have not attracted researchers; and care-giving roles have been almost entirely overlooked, with the notable exception of parenting (see below).

Intimate and sexual relationships are an area of particular sensitivity as far as people with learning difficulties are concerned. I commented in Section 1 that one of the motives for segregation of ‘mental defectives’ in the early twentieth century was fear of their promiscuity and of hereditary defect, and that women were

targeted. Both Jenkins (1989) and Brown (1994) argue that this has not changed substantially, though the ideology is less overtly repressive, and the case for restriction of sexual activity is framed in terms of protecting the innocent (Brown 1994:130). Burns comments on the asexuality of group home living as a means of maintaining people in a state of 'suspended adolescence', a device to inhibit procreation (1993).

What this has meant for research is that there is relatively little in depth research on the topic of intimate relationships. Studies of marriage are rare. Mattinson (1970) and Craft and Craft (1979) found that despite the difficulties, people valued marriage as a relationship which offered status, as well as psychological benefits, and opportunities for reciprocity. Richardson and Ritchie (1989) discuss marriage in their study of friendship, describing it as 'a valued opportunity to give' and 'a source of pride'. Flynn (1989) included nine co-resident couples in her research into community living. The findings suggest varied levels of satisfaction, but significantly Flynn remarks 'It seems possible that the preparation of adults for independent living blurs the traditional male and female household roles .. all the men (with one exception) involved themselves in routine household tasks' (1989:80), though the detailed cases quoted suggest considerable variation.

Homosexuality has been invisible in the literature until very recently. Thomson and McCarthy (forthcoming) argue that men with learning difficulties do engage in homosexual activity, but are unwilling to discuss it; and that homosexual relationships between women are completely undocumented. Some practitioners argue that the pressure to conformity is such that alternative sexual options for women are virtually impossible (McCarthy 1991).

Parenting is virtually the only caregiving role occupied by people with learning difficulties to have attracted researchers. Interest has been in them as a 'problem group', largely because of the eugenic fears which have inhibited people from

marriage or sexual activity. Booth and Booth (1993a) argue 'Most research has been conducted from a clinical, developmental or behavioural perspective which has tended to treat the parents as little more than dependent variables in the analysis rather than credit them with any integrity as people'. Genetics, assessment of parental competence and the risks of child mistreatment or abuse have been subjects of interest (Tymchuk and Andron 1988, Attard 1988), though two British studies have emphasised that poverty and deprivation are as much to blame for difficulties experienced by parents as individual deficits (Mattinson 1970, Booth and Booth 1994).

### *Gender*

'Women are all but invisible in the literature and the making of policy about disability' (Lonsdale 1990).

In discussing social relationships I have alluded to the impact of gender where research has made it a focus of attention. However, as few studies of peoples' social relationships identify gender as a significant variable, it is important to devote some space to it. The lack of interest in gender is in itself noteworthy, reflecting perhaps a lack of interest, or an absence of gender differences, though it seems likely that the tendency to portray people with learning difficulties as asexual (Brown 1994) is also responsible. There has, however, been interest in the gender of caregivers (see above, Section 2, also Traustadottir 1991), and some authors have pointed out that 'dependants' are women too (Morris 1992a, Williams 1992).

Gender blindness on the part of researchers has been noticed by Brown and Smith (1992a) who argue that the principle of normalisation may be partially responsible. It offers a remedy to social devaluation which requires 'passing' as normal, accepting low paid jobs, and eschewing contact with others labelled as having learning difficulties. For women, this may mean acceptance of servile roles and abuse: 'New services have tended to imitate the nuclear family in grouping together

in small houses, women in these groups are likely to find themselves in a 'housekeeping role' .. servicing men whom they have not chosen and with whom they do not have close personal ties' (Brown and Smith 1992a:159-60).

Williams (1992) suggests that women's caring responsibilities in the home may effectively trap them in the private sphere, rather than give them access to the public domain. Noonan Walsh's research in Ireland tends to corroborate this (1988). She found that women were more able at domestic tasks than men, but led more restricted lives. Flynn frames the link with caregiving more positively; she found 'Women have more positive relationships than men' (1989:119) and speculates that this is associated with women's socialisation into 'caring for others'.

Dorothy Atkinson and I have examined the personal testimonies of women with learning difficulties, and found 'Some women felt oppressed and burdened by their domestic work, whilst others derived satisfaction from being able to look after themselves and people they are close to' (Atkinson and Walmsley forthcoming). This seems to parallel research findings in the context of family care for older parents; that caregivers' reactions to their duties vary (see for example Lewis and Meredith 1988).

Self Advocacy has been slow to develop a feminist dimension. Thomson and McCarthy found most self advocacy groups are dominated by men (forthcoming). Sutcliffe (1991) found few women's groups operating, and a Women's Conference held in 1992 which addressed issues such as abuse, racism, friendships and caring (Walmsley 1993d) was claimed to be the first of its kind. Hutchinson et al address double discrimination from the perspective of women with learning difficulties (1992).

These are only beginnings. Research into the impact of gender on the relationships of people with learning difficulties is in its infancy. and few links have been made to peoples' experiences of giving and receiving care, an area which this research

explores in some detail.

So far in this section I have reviewed the literature on the social relationships of people with learning difficulties. There has clearly been more interest in them as people needing care and support than in their roles as caregivers or equal partners. It is a matter of interest that, though it was once official policy to use the labour of mental defective patients in hospital to care for others (Ayer and Alaszewski 1984, Thomson 1992), these roles as caregivers have been largely overlooked, whilst people's needs for support, help and intervention have been studied exhaustively, and suggests that the ideological framework of 'dependent' has coloured the way researchers have looked at social networks and relationships, even where there is data which is subject to other interpretations.

This is partly the result of methodological approaches which ask for caregivers' opinions, but even where people with learning difficulties are the main informants their support needs are often of primary interest (e.g. Atkinson 1986, Richardson and Ritchie 1989). The methodological issues are revisited in Chapter 3, but in Section 4 below I look at the findings of research into how people construct their personal identities.

#### **Section 4 Personal Identity, Care and Dependency**

I noted in the Introduction the sharp divide between research which sees people as a dependent group, influenced by trends in social policy, and a disability rights perspective which seeks to 'give voice' to people. Much of the research summarised in Section 3 relied on the views of 'carers', but research in which people with learning difficulties talk about themselves shows that personal identity is at variance with the social identity of 'dependent'. The methodological antecedents of this approach are discussed in Chapter 3. Here I summarise two aspects of that research, the extent to which people identify with the label 'mental handicap' or 'learning difficulty', and the degree to which people represent

themselves as givers or receivers of care. Regrettably, no research in this area has focused on gender.

Research into the degree to which people with learning difficulties identify with that label suggests considerable variations. Jahoda et al found that their informants 'were aware of the stigma associated with being identified as a mentally handicapped person' but 'they did not accept that this meant they were less worthy as persons' (1989a:153-4). Jenkins and Aull Davies (1991) found that the young people they asked appeared not to recognise 'mental handicap' as being applied to them. Introducing their anthology, Atkinson and Williams comment, 'These reflections suggest that most of the contributors do not identify themselves first and foremost in terms of their impairments' (1990:11). Simons (1992) shows that self advocates were both aware of being labelled, and willing to discuss its implications. All preferred 'people with learning difficulties' to 'mental handicap', though there was variation in the degree to which people were prepared to accept being labelled at all.

The research is inconclusive, but suggests that self advocates are more aware of the implications of being labelled than other people with learning difficulties and more prepared to apply a label to themselves. The reasons for this may be that staff and families treat disability as a taboo subject, 'many people with learning difficulties have not had the chance to explore what that difference means to them' (Simons 1992:29). This conspiracy of silence has been attributed to normalisation (Chappell 1992), and there are arguments for a reversal of this through consciousness raising (Williams 1989, Szivos and Griffiths 1990).

Though it has not been addressed specifically there are indications that people associate the label 'mental handicap' with dependence. In Simon's research people rejected 'mental handicap' on several grounds including 'It means we can't do anything for ourselves and we need support all the time which we don't' and 'It

makes people outside see us as children to pity' (1992:24). Many people with learning difficulties do not share the view of themselves as dependants which pervades the literature on care: 'Delegates were anxious to help people more handicapped than themselves'; 'Helping other people was, for many of the delegates, the best work there was' (CMH 1982:10); 'My mum died when I was small so now I look after my dad. I can't leave home because he needs me' (Atkinson and Williams 1990:175); 'Again and again the self advocates would point out how they were making some kind of contribution to the community around them .. helping others was a central issue'; 'Helping people worse off than yourself'; 'Find out what it's like when people are in hospital and how to help them' (Simons 1992:18 and 28). The language here, though, is different to that used by academics and policy makers, in that 'help' and 'looking after' are used rather than 'care'.

Simons found that people did acknowledge that they were also in need of help from others, though 'If asked directly if they found anything difficult many would initially say no' (1992:26). The salience people with learning difficulties give to their helping activities suggests that these are important to them. A link can be made with people's ambivalent attitude to their labels, and perhaps more broadly to the valued statuses of adult and citizen which are associated with autonomy and respect, rights and responsibilities, and not with the marginalised status of dependent (Walmsley 1991b, Hockey and James 1993, Johnson 1993).

## **Conclusion**

In this chapter I set out to show how people with learning difficulties have come to be seen in research and policy terms as dependants. Amongst adults they are perhaps the quintessentially 'dependent group', burdens to their families and to the state, in the needs rather than the rights group in society (Stone 1985). I have argued here that much research into the social networks and relationships of people

with learning difficulties has been based on a prior assumption of their dependency, and that this has been influenced by the wider research agenda into informal family based care. I share Morris's view that such approaches unhelpfully polarise the interests of carers and dependants and have facilitated, rather than challenged, the oppression of both groups. The emphasis in learning disability research and practice on the superiority of family based care tends to infantilise the recipient of that 'care', and, perhaps not accidentally, serves the interests of governments which seek to keep costs to a minimum.

The significance of analyses which define people with learning difficulties in terms of their care needs is that to be seen solely as a dependent is stigmatising and undermines adult status and citizenship. This is challenged by research which allows people to articulate their own views. This produces a more diverse picture, of people who see themselves as much helpers as helped, as much caregivers as cared for, as much lookers after as looked after. In Chapter 3 I develop this theme by examining how different methodological approaches have influenced the way people with learning difficulties are represented in research.



## **Chapter 3: Research Methodology: a Literature Review**

### **Introduction**

In this chapter I discuss in more depth the methodological issues raised in Chapter 2. The chapter acts as a justification for my choice of method, semi-structured biographical interviews, supplemented by other historical sources, described in detail in Chapter 4.

In particular I link the growth and principles of self advocacy amongst people with learning difficulties to qualitative research which seeks to find ways of giving people with learning difficulties a voice, and then set qualitative research with people with learning difficulties within a wider research tradition which encompasses life histories and stories, oral history and biography.

Finally I identify issues raised in the research methodology literature which relate to the method I chose.

### **The Research**

I set out to find out what care and caring mean to adults with learning difficulties. The rationale for this is set out in Chapters 1 and 2. There were three principal strands to the research: biographical interviews with adults with learning difficulties

- to discover how they describe care and caring; oral history interviews with people who were in a position to provide information on changes in learning disability services locally; and documentary research into the operation and development of learning disability services in the locality.

### *Choice of method*

The choice of biographical interviews with women and men with learning difficulties was influenced in part by the gaps identified in Chapter 2. There I highlighted some critiques of the methodological approach taken in the literature on gender, caring and learning disability.

To recap, research interest in the experiences of informal care within the family has developed in parallel with the development of critiques which focus on the oppression of disabled people, yet few researchers have asked for the views of 'care recipients' as Jenny Morris's recent work shows (1993a). The assumption is that some people give care and some are recipients of care. There is no recognition that people may occupy both roles simultaneously.

The feminist literature on caring has tended to focus on the experiences of the givers of care. Qualitative studies, such as those by Abbott and Sapsford (1987), Lewis and Meredith (1989) and Grant and McGrath (1993) seem to objectify the recipients of care, and disregard social characteristics such as gender, class, race. Few researchers have focused on gender and learning disability, except insofar as the gender of the family carer has been of interest (Traustadottir 1991, Wickham Searle 1992). The samples on which many studies on caring are based have excluded the possibility that disabled people, including people with learning difficulties, may have views on the experience of dependence, indeed, may also be carers. Quantitative studies, including the work based on the 1980 General Household Survey by Arber and Gilbert (1989), and the 1988 Office of Population Censuses and Surveys discussed by Abberley (1993), have also assumed that there is a class of people called 'disabled', without prior investigation of that status. The effect has been to dichotomise carers and dependants as if there is no overlap, and no interdependence or reciprocity.

These omissions have been vigorously challenged by disabled people (Morris 1991, Keith 1992), but the analysis of learning disability is marginal. Studies in which people with learning difficulties have been asked for their views, and have been able to speak for themselves are rare and relatively recent, and none focused either on the experience of care per se, or on gender. I discussed in Chapter 2 possible reasons for this: that people with learning difficulties are seen in terms of their

support needs, or the support needs of their carers, and that people with learning difficulties are expected to be asexual.

Finally, research both on learning disability and on caring has tended to take a snapshot view, via network analysis, for example, or through the collection of statistics based on the General Household Survey (Parker and Lawton 1994, for example) and is rarely grounded in people's biographies or contextualised historically. Thus the possibility that care relationships change over time has not been explored in depth, nor has the impact of socio-historical change on the individual life course.

It is these factors which influenced the choice of method in this research, biographical interviews focusing on the experiences of care and caring to explore the issues of gender, learning disability and caring. The method was chosen to allow men and women with learning difficulties to speak for themselves about their experiences of caring. In addition, I sought to contextualise these experiences historically, both through the individual biography and through oral and documentary research into the way policies on learning disability have changed over time.

In the next section I set out the context for the use of personal testimony in research into learning disability.

### *Finding a Voice: Self Advocacy and its impact on research*

In recent years people with learning difficulties have begun to 'find a voice' largely through self advocacy and self advocacy groups (Crawley 1988). It is perhaps no accident that research projects which seek to give a voice to people with learning difficulties have proliferated as self advocacy has developed. The first British People First Newsletter was published in 1985, and it is since that date that the majority of research which involves people with learning difficulties has been

undertaken (see below). Gerber observes 'it may soon be difficult to recall that a short time ago people with disabilities were little more than objects of study' (1990:4). In 1984 Richards could find only five British studies in the previous ten years which had used people with learning difficulties as key respondents. Ten years later, such research is much more common, as I will show.

Linking self advocacy with research, however is not straightforward. Whilst it is possible to point to research publications by disabled people which are associated with user movements (for example Oliver 1990, Morris 1989, 1991) no such body of writing exists by people with learning difficulties and they are more frequently subject to being represented by others, such as researchers. There are some publications by people with learning difficulties, but few of these would be considered to be research. Examples are autobiographies such as Hunt (1967) and Deacon (1974). Subsequently there have appeared some imaginative conference reports which use the words of participants (CMH 1982, Islington Disablement Association 1992, Nottingham Advocacy in Action 1993). Training materials like 'Oi it's my assessment' and 'Everything you ever wanted to know about safer sex but nobody bothered to tell you' (People First 1993 a and b) were created by and directed at people with learning difficulties, and some published chapters have been co-written by people with learning difficulties (Etherington et al 1988, Amans and Darbyshire 1989).

Though self advocacy has influenced researchers, it is hard to find examples of research controlled by people with learning difficulties. Zarb (1992) and Ramcharan and Grant (1992) discuss the structural barriers to research controlled by disabled people including people with learning difficulties. Some progress has been made in research initiated and controlled by people with physical disabilities (for example Morris 1993a), but it remains the case that whilst people with learning difficulties do participate in research, it is invariably research initiated by others

(Walmsley 1994).

However, it is clear that the principles of self advocacy have influenced researchers, for example People First's slogan, 'Label jars not people' (People First 1993c) is quoted by Booth and Booth (1994) as a basic principle of their work. There are also examples of self advocates generating theoretical challenges to the status quo. Northamptonshire People First contest the validity of 'care' as a concept 'We are weary of the term 'community care' because it implies we need caring for rather than supporting us to live our lives in the community' (Northamptonshire People First 1993). Such analyses have developed from sharing ideas and personal experiences in groups, and are important sources of inspiration for research; but for the present the main body of research is created by others, sometimes in partnership with people with learning difficulties.

Partly in response to the demands of self advocacy a whole array of research methodologies has been used by researchers seeking to involve people with learning difficulties. These are described in the next section, and are contextualised in the broad sweep of research based on personal oral testimony.

#### *Biographical research: a spectrum of approaches*

The broad biographical tradition encompasses many variants on a spectrum delineated by Plummer (1983) using both the degree of editorial intervention and the published outcomes as criteria. Thus a completely unedited spontaneous account is at one end of the spectrum whilst the use of personal documents (diary extracts, photos, quotations) to illustrate an argument or hypothesis created by the author is at the other.

Encouraging people to tell their own stories has been seen as a means of 'giving voice' to marginalised groups traditionally outside the mainstream of writing and research whose perspectives are not to be found in conventional sources (Bornat

1992). This is research in which people are invited to give subjective accounts of their lives. Reinharz (1992) describes feminist research projects as a way of 'gaining access to peoples' ideas, thoughts and views in their own words .. learning from women as an antidote to research which ignores women's words altogether or having men speak for women' (1992:19). Also in the context of feminism Lather argues that such methods can 'help participants to understand and change their situations' (1986:263). Mishler (1986) and Lincoln and Guba (1989) argue for research to be empowering. Palmer et al (1992) underlined the theme of empowerment in their project on racism by labelling interviewers as 'listeners' and interviewees as 'historians'. In gerontology McAdams (1990) links the telling of the life story to identity, believing that it is maintained by the making and remaking of the life story. Knowledge of an individual's biography has been seen as a way to improve standards of care for vulnerable groups of older people (Johnson 1976). Adams discusses the importance of reconstructing a personal history for 'the institutionalised patient who is diagnosed as suffering from dementia of the Alzheimer type' (1989:62). Kohli (1985) speculates on the significance of the unique biography in a world of increasingly standardised norms. Evans claims 'The use of biography is not just to illustrate a social theory but to explain its meaning' (1993:12). Bornat writes 'First person accounts and insights into the lives of oppressed and previously unremarked groups and individuals possess the moral high ground with their unchallengeable authenticity' (1992:24). It is against this background that qualitative research with people with learning difficulties can be viewed.

In order to position the literature in learning disability within this spectrum I survey the variety of approaches encompassed therein, and discuss what work has been done within those contexts on learning disability. I use the following categories: 'Whole Life Approaches', 'Topic Based Research', and 'Oral History'.

### *Whole Life Approaches*

One important research focus is the whole life. What distinguishes this range of approaches is that the researcher seeks to create a rounded picture of the research subject's life, rather than use the information to illuminate a particular topic.

Individual life histories written by sociologists identified with the Chicago School (Plummer 1983) are the product of a collaboration between the 'subject' and the author and are methodologically open ended 'you should try to include all of your data which could change any interpretation of the person's life and experiences' (Taylor and Bogdan 1984:143). Published life stories in this tradition tend to focus on outsiders. They include the life story of a hobo (Anderson 1923), a criminal (Shaw's *The Jack Roller* 1930), and a man labelled as having learning difficulties (*Inside Out: the Life of Ed Murphy* Bogdan and Taylor 1976). The approach taken by researchers in this tradition tends to present people as human beings above all and to challenge the stigmatising label. Drawing on their life story work with Ed Murphy, the researchers conclude: 'Our research suggests that the concept of mental retardation is not just less than useful, it is seriously misleading' (Bogdan and Taylor 1982, reprinted in 1989:76).

Multiple life stories such as Campling's *Images of Ourselves* (1981) and Morris's *Able Lives* (1989), both by disabled people, Jewish Women in London's *Generations of Memories* (1989) and the Hall Carpenter Archives' *Inventing Ourselves: Lesbian Life Stories* (1989a) and *Walking After Midnight: Gay Men's Life Stories* (1989b) represent groups, like people with learning difficulties, whose stories have been 'obscured or absorbed' (Jewish Women in London 1989:8). The argument for such collections is the importance of the representation of the subjective experiences of people who are frequently portrayed by others as deviant in some way. Some collections also emphasise the interplay of historical forces and individual biographies. Jewish Women in London, for example, focus 'on the way

in which historical time and place and personal experiences are lived out by individual women' (ibid 1989:9).

There are examples of such collections in the literature on learning disability, for example *Lifelines* (Humphreys et al 1987) and Felce and Toogood's *Close to Home* (1988), but these are less evidently the voices of the contributors, being compilations of life stories developed from a whole variety of sources - family, staff, documents. In this research mode, from the very way such collections are conceptualised, the emphasis on the 'label' is present throughout. People are chosen to contribute because they represent a particular stigmatised group, and that is where the interest lies.

A variant of multiple life histories is the anthology. This has been pioneered within disability, for example anthologies of writings by disabled women such as those edited by Browne, Connors and Stearn (1985) and Saxton and Howe (1988). In the context of learning disability this approach appears in *Secret Lives* (Ward 1989) and was further developed by Atkinson and Williams (1990) who created an anthology of prose, poetry and art by people with learning difficulties. Anything was accepted on any topic - 'in producing and submitting their "stories" people with learning difficulties would be setting the agenda and providing the contents which would be central ..' (1990:5) and it was the job of the editors to make sense of a mass of contributions in a variety of formats - written, pictorial, tape recorded. The editors discovered that people's common human experiences often override their differences from others. Much of the book is about relationships, memories, childhood and family, and relatively small sections directly address the impact of the 'learning difficulties' label. In this sense they share Bogdan and Taylor's findings (1982) that the label is misleading, 'It challenges our assumptions and stereotypes even when we think we have none' (Atkinson and Williams 1990:7).

It is significant that more open ended research approaches suggest that the 'primary



social identity' (Jenkins and Aull Davies 1991), that is, being a person labelled as having learning difficulties, is not congruent with the way people present themselves in research when they have the choice. People will tend to describe themselves and their experiences in a way that emphasises what they have in common with others, not their differences.

Many researchers have used life histories as a source of sociological or historical information. Bertaux (1981) exemplifies this approach. His abstractions from the biographies of French bakers he collected were used to develop the typical career of this group, and to identify the dominant factors which influenced variations. Elder's *Children of the Great Depression* (1974) is a classic example of a project which examined the impact of changing historical time on the lives of individuals, through comparing the life course of people born a generation apart. No studies of learning disability have been as ambitious as these enterprises, though perhaps Edgerton's ethnographies are as close as any. He conducted a series of studies of people who left a California hospital in the fifties, the first of which, *The Cloak of Competence*, was published in 1967. Forty-eight people are portrayed as complex human beings, capable of speaking for themselves. Individual life stories comprise the main data. Edgerton accepted 'mental retardation' as a given and confined his interest to how people negotiated the associated stigma, taking his cue from Goffman (1961): he argued for 'a general description of the lives of mentally retarded persons in the community (proceeding) to a specific discussion of the problems they face and the techniques they employ in dealing with their stigma and their incompetence' (1967:xiv). He found that people struggled to 'pass' as normal, and employed various stratagems to enable them to do so, including seeking out 'benefactors' (Edgerton 1967).

The limitations of research which fails to question the labelling process are pointed out by Gerber (1990) who criticises Edgerton for his 'uneasy combination of

empathy and acceptance of mental retardation as an unalterable condition' (1990:3) which he says denied people a voice to speak authoritatively about their own situation. As an example he cites statements quoted by Edgerton such as 'I know I can't talk as good as most people. Even my friends tell me I'm hard to understand but that don't mean anything. That's from being in the colony so long.' (1967:170). Edgerton sees this as a rationalisation to bolster self esteem; but it could be seen as an insight into the social processes which create the labelled identity.

Edgerton's latest study (1989) suggests that he has modified, but not abandoned, the concept of mental retardation as a property of individuals as opposed to a socially created identity. He notes that the individuals he followed up, now elderly, live full and satisfying lives which are not dissimilar to others of similar age and socio-economic status 'the older mentally retarded people in this sample are as normal as anyone among us' (1989:187).

Booth and Booth (1994) argue that their approach 'depth interviewing to compile life stories' is preceded only by Edgerton (1967) in the learning disability literature. Their book comprises both life stories and analyses of the experience of parenting based on biographical data.

These 'whole life' approaches cover a spectrum of methods. In some instances the data was collected through interviews (Edgerton 1967, Bogdan and Taylor 1976); in others, most notably the anthologies, accounts were written or co-written by the contributors and edited by the authors (Atkinson and Williams 1990, for example). Booth and Booth's attempt to co-write with their interviewees the findings from their interviews represents an attempt to meld the two approaches (1994). Overall, these 'whole life' approaches tend to emphasise what people with learning difficulties have in common with others, though Gerber's critique of Edgerton's work suggests that the researcher's frame of reference can modify this. My next Section, 'Topic Based Research' provides a contrast with the 'whole life' approach.

### *Topic Based Research*

Moving from the whole life approaches discussed above, the use of semi-structured interviews has been a popular way of eliciting perspectives on particular topics. Graham (1984b) claimed that 'The use of semi-structured interviews has become the principal means by which feminists have sought to achieve the active involvement of their respondents in the construction of data about their lives'. Examples of such approaches are numerous and include Oakley's work with pregnant women (1981), Russell's study of marital rape (1982) and Finch's interviews with clergy wives (1984b).

Researchers were initially cautious in applying such methods in learning disability research. Two well known studies of the mid eighties, by Margaret Flynn (1986, 1989) and Dorothy Atkinson (1986, 1989), incorporated semi-structured interviews, but included other data sources, such as interviews with social workers and case notes so that the data could be corroborated. Both found that in retrospect their interview material was of primary importance, and include numerous quotations from transcripts in their publications, but safeguards against the presumed inadequacy of people with learning difficulties as informants were seen as important at the outset.

The increasing trust of British researchers in people with learning difficulties as informants began to become evident in the late 1980s. Research sponsored by the Scottish Home and Health Department marked a transition to making people with learning difficulties the primary informants. Research papers on independent living (Markova, Jahoda and Cattermole 1988a), on hospital life (Cattermole, Jahoda and Markova (1988b), on Adult Training Centres (Jahoda, Markova and Cattermole 1989a), and stigma and self concept (Jahoda, Markova and Cattermole 1989b) give the views of people with learning difficulties on these topics. The finding that 'There is a major difference in the conception that people with a mental handicap

and staff have of training for independent living and living independently' (Markova, Jahoda and Cattermole 1988a) emphasises the importance of seeking the views of both service users and staff.

Jenkins and Aull Davies used semi-structured interviews with young people with learning difficulties to explore an abstract theme, identity. They found that 'the majority .. do not comprehend the terms most commonly associated with their primary social identity' (1991:8), that is, they do not apply the terms 'mental handicap' or 'learning difficulties' to themselves.

Ken Simon's research with self advocacy groups to find out what 'users' empowerment and participation can mean in practice' (1992:4) suggests that members of self advocacy groups were aware of the implications of labelling, and recognised that labels apply to them. Despite this 'many self advocates retained a positive sense of self, emphasising their abilities and the contribution they make to the community' (1992:30). The contrast with Jenkins' and Aull Davies' findings (1991) may in part be attributed to the fact that Simons worked with groups, not individuals.

Grant, Ramcharan and McGrath pioneered methods which could include people with less well developed communication skills and used a variety of methods to do so including 'observational techniques', 'interviews, discussions, prompt cards and accompanying people in their daily lives' (1993:3). They also interviewed others in the network: key workers and family members. Their first publication from this work describes the lives of three people. The authors aggregate information from a variety of sources, including key workers and family, into a third person account illustrated with quotations and use this to structure a discussion around themes such as 'Life at Home' and 'Participating in the Community' (Grant, Ramcharan and McGrath 1993).

What emerges from the semi-structured topic based interview research described

here is that many people with learning difficulties are able to respond to such approaches, and can provide valuable antidotes to prevailing assumptions about their lives, but that there is a problem when interviewing about abstractions, such as identity in that such terms are hard to present and tend not to be recognised by participants. The challenge of eliciting the views of people with less well developed oral skills remains, and Grant, Ramcharan and McGrath's work demonstrates the difficulties in allowing such people 'a voice'.

A further issue is who sets the research agenda. In these topic based research projects the questions were set by researchers without learning difficulties. When I undertook interview based research to discover what meanings some Adult Training Centre users attributed to adulthood, using a mixture of group and individual interviews, I found that adulthood 'was simply not on the group's agenda' (1991a:147) and instead focused on an issue which was a preoccupation, independent living. I pointed to this as an instance of the importance of allowing the interviewees to set the research agenda. The importance of recognising that the product of an interview depends both on the researcher and the interviewee (Stuart 1992) is of particular significance in the context of research with people with learning difficulties because they are rarely in control of the research process. These issues are beginning to be explored, and I describe this in the context of oral history.

### *Oral History and Reminiscence*

According to Frisch (1990) oral history is two things - 'more history', a new source of historical evidence, and 'anti history', a way of revealing alternative perceptions of the past and gaining access to personal experiences of the past. Oral historians set out to answer historical questions by means of collecting oral evidence (Thompson 1988) and there are a huge number of examples. The significance of oral history for rewriting history from the point of view of people who leave few

written records has been a motivating factor, well known examples being the work of Ewart Evans (1956) on agricultural labourers and Samuel (1975) on quarry workers. There are, however, few examples from people with learning difficulties. Thompson's seminal *Voice of the Past* (1988) does not mention any.

The rarity of historical accounts which draw on the evidence of people with learning difficulties, either for 'more history' or 'anti history' is striking, particularly as for people who are rarely or barely literate oral history is uniquely appropriate. Potts and Fido's work on 'the colony' is an example both of 'more history' and of 'anti history' (Fido and Potts 1989, Potts and Fido 1991). They draw on oral history accounts from patients to reconstruct the experience of being in a mental handicap hospital (colony) in the twentieth century. The research focused on one institution, and used individuals' reminiscences to create its history, though the researchers also used documentary sources to supplement and contextualise their findings. Humphries and Gordon's *Out of Sight* (1992) is also an example of an attempt to bring the history of disabled people into focus. In their introduction they argue that 'The experience of physical disability is almost completely undocumented' (1992:9) and through their interviews with disabled people born before World War Two they 'contribute to the rewriting of the history of disabled people from their own point of view' (1992:10). It is another example of 'more history' and 'anti history'.

Atkinson (1993a, b, c) describes a project which incorporates features of both oral history and reminiscence. There is a dual purpose of eliciting both individual stories and collective accounts which throw light on the experience of being a person with learning difficulties in the second half of the twentieth century. Atkinson's approach was distinctive in that she took an interest both in ordinary memories - of childhood, relationships, work - and special memories unique to people with learning difficulties - being 'put away', and life in hospitals. She was also

concerned to explore the 'how' of history, and explains how producing a book of people's memories part way through the project gave her group a sense of creating history which was initially absent, and began to redress the balance of power between her as the researcher and the group members: 'Somehow the ownership of the project had shifted, and I had become its servant rather than its instigator' (1993b:206).

Stuart (1992) develops the 'how' of oral history further by discussing the impact she as an interviewer had on her interviews, and the impact her research had on her. She emphasises the importance of recognising the way 'meanings are contested and created in the moment of the interview' (1992:81, see also Dunaway 1992).

The amount of published work based on the historical testimonies of people with learning difficulties is small, though I am aware of a number of projects in progress (Ramcharan 1994, Stevens 1994, Gladstone 1994, all personal communications). So far most research has focused on 'more history' and 'anti history', in particular shedding light on the way institutional life was experienced. The 'how' of oral history with people with learning difficulties has been little described: Potts and Fido (1991), for example, do not problematise the research relationship. However, some issues which arise have been explored in the wider literature on biographical research where the respondents are members of marginalised groups, and these are discussed in the final part of this Chapter.

### *The Case for Biographical Interviews*

The burgeoning of biographical research with people with learning difficulties in the past decade appears to have been influenced both by the development of self advocacy with its emphasis on 'finding a voice' and the growing interest in such methods in the literature more widely, often influenced by feminist research. The spread is wide, from the in depth life history to topic based research 'in which the object of research enters into the process as an active subject' (Acker, Barry and

Esseveld 1982:6 quoted in Finch 1984b). This body of research 'challenges most fundamentally the idea that people with learning difficulties have no capacity for understanding their own situations, or their own feelings, or their own deprivations' (Atkinson and Williams 1990:8). In that respect they differ little from other groups who have been 'marginalised and oppressed groups in society' (Shakespeare et al 1993:2). However, whilst there are parallels, there are also differences, highlighted in this chapter. People with learning difficulties do not appear as authors in their own right. Usually they are represented by others, sometimes with sensitive use of their own words, but always managed in some way by the author whose name is cited. The research methodology appears to dictate how they appear. Open ended research, such as that by Bogdan and Taylor (1976) and by Atkinson and Williams (1990), shows them as people first and foremost and their label as secondary. But in most of the research cited here they appear as commentators on their distinctive experiences - the Adult Training Centre, the colony, deinstitutionalisation.

Drawing on this body of research, I made the choice of undertaking biographical interviews with people with learning difficulties. These are described by Cornwell and Gearing as based on the assumption that the beliefs and ideas people have about, in their case, health and illness, 'will be connected in some way to their lived experience and therefore our understanding of their views will be improved by knowing something about the contexts from which they have emerged' (1989:36). Biographical interviews thus combine a whole life approach with a focus on a particular topic, in this research, care and caring. The decision to supplement the biographical interviews with documentary research owes much to oral history methods where the researcher is advised to inform herself on the context of the informants' lives (Thomson 1988). However, the interrelationship of the historical information and the biographical interviews is more complex than this formula suggests. Biographical interviews, though not specifically designed to elicit



historical data, do have that capacity, and the interviews I did yielded data which is historically valuable, as well as shedding light on people's perceptions of care and caring.

Initially, I saw the task as examining a topic determined in advance, an exploration of caring through biographical interviews. However, in reviewing the literature, I became convinced that such an approach limited the extent to which individuals could represent themselves - they were disembodied to create an academic argument. I therefore decided to include four auto/biographies which stand as whole lives, albeit mediated by my authorial stance (see Chapter 7). I also elected to discover the context in which people have lived through historical research, both oral and documentary, into the way learning disability has been viewed and managed in Bedfordshire.

Thus I drew on all three approaches described above - whole life, semi-structured interviews around a particular topic, and oral history - in undertaking the field work for this thesis.

There remain certain unresolved issues in creating a research framework wherein people can genuinely speak for and represent themselves, and these are discussed in the next and final Section.

### **Methodological issues**

Certain methodological issues recur in the literature on biographical research methods. They apply equally to research with people with learning difficulties, though the latter throws up some issues, such as finding respondents, which are less fully echoed in mainstream literature; and the research on learning disability does have important contributions to make in areas which are well covered in the general literature. I set out here to discuss some of the issues which exercised me in undertaking this thesis in the light of the work of biographical researchers in

learning disability and more generally. This final section explores some of the challenges in creating research partnerships. How these were resolved is discussed in detail in Chapter 4.

#### *Evolving the idea and agenda setting*

I identified above a range of approaches, from the open ended detailed life history to topic based research drawing on personal testimony, and observed that the former tend to produce results which emphasise that people with learning difficulties are 'people first' while the latter confine people within the context of learning disability. This tension is well expressed by Atkinson (1993a) who set out both to find out about the experiences of people labelled as having a learning difficulty but also to 'normalise' the experiences as human, hence her recourse to reminiscence aids - domestic artefacts from the period when her respondents were children - to stimulate memory. This dual purpose is echoed in *Jewish Women in London* 'the impulse ... was not just to find out but to challenge the stereotyped assumptions about who Jewish women were and what their lives were like' (1989:8). The challenge of agenda setting, allowing the participants to dictate the content while retaining a focus is exacerbated in learning disability research by the exclusion of people with learning difficulties from the funding and initial stages of research (Ramcharan and Grant 1992), and by communication problems within the research relationship, a set of issues explored by Brechin (1993).

#### *Approaching Respondents*

Finding people to interview is something that the wider literature does not often highlight - Plummer's (1983) advice is that subjects 'should be fairly articulate, able to verbalise and have a good story to tell', whilst Thompson (1988) hardly touches on it in the context of oral history. An exception is Foot Whyte whose *Methodological Appendix to Street Corner Society* (1955) gives a graphic and humorous account of the way he got in to Cornerville, and it is perhaps in

anthropology that getting into the field is most widely explored (Peberdy 1993). Finding respondents throws light on the perceived differentness of people with learning difficulties, and the stigma associated with the label. Hall Carpenter Archives' *Lesbian Life Stories* (1989a) do not problematise the status of lesbian as one their contributors might not wish to own, perhaps because within their particular context 'lesbian' was a label to wear with pride. It appears, though, that researchers with people with learning difficulties are not always specific in telling their participants that they are of interest because of their label, because it indicates a stigmatised identity with which they may not identify. Thus recourse is made to insider status (Atkinson was a social worker in the area where she carried out her research on hospital leavers (Atkinson 1986)), or intermediaries (Flynn 1989, Atkinson and Williams 1990, Todd and Shearn 1992, Booth and Booth 1993), or 'captive populations' in hospitals, ATCs etc. (Jahoda, Markova and Cattermole 1989a, Walmsley 1991a, Jenkins and Aull Davies 1991). Few research projects have been able to draw on a wide and diverse population through public advertisement because people with learning difficulties are often unable to read, and even if they can do so are often too poor to regularly buy newspapers or magazines (Booth and Booth 1994). Atkinson and Williams found contributors by advertising in magazines and journals, and by contacting people in their existing networks. They worked through 'intermediaries', people who already knew the contributors well, and would support them in 'telling their stories' (1990:10).

Access to respondents is particularly problematic with people with learning difficulties, and throws light on the barriers which exclude them from normal patterns of life, and on the stigma associated with the label. It may well also have a bearing on the data collected because researchers appear as allies of service providers, family or others and may continue to be perceived as such. This problem was highlighted by Bercovici when describing her research into the experiences of

some adults with learning difficulties recently discharged from hospitals: 'It took many months to convince 'natives' of this system that the researcher was not part of the collaborative network they saw as an immutable part of social life' (Bercovici 1981:139).

### *Research relationships and empowerment*

The social relations of research have been a preoccupation in feminist research for many years (see Bowles and Duelli Klein 1983). Mies (1983) argues that when people from 'underprivileged' groups are being interviewed by people from a higher social stratum it has been observed that the data thus gathered often reflects expected rather than 'real behaviour'. This tallies with research in learning disability undertaken by Seligman et al (1981) who found that asking closed questions to people with learning difficulties tended to produce acquiescence. Flynn also argued that people will try to give answers which please the interviewer (1986). More recently, disabled people have begun to challenge research into disability which is funded and carried out by able bodied people as oppressive rather than enlightening (Oliver 1992, Zarb 1992).

These observations give rise to questions about claims to empower marginalised groups through research. In her review of Gluck and Patai's *Women's Words* Chamberlain chronicles the disenchantment, the ethical dilemmas, the dubious claims made for oral history as a route to empowerment: '(we thought) oral history not only provided access to areas of women's lives denied in conventional sources. It also gave women a "voice". It empowered them....Far from being non exploitative and democratic, many oral historians made their reputations on the backs of informants, historical specimens plucked from, then returned to obscurity' (Chamberlain 1992:71-72).

The claims made for participation in research to be empowering have been discussed above, but how far can research be genuinely participatory and non

exploitative? Consent, for example, is widely aired in the literature, often on the assumption that the interaction is between equals. Thus Thompson writes: 'a person who, knowing that a historian is collecting material for a research study, agreed to be interviewed, would have little ground for complaint if he found himself quoted in print' (1988:224). The key word here is 'knowing'. How can the respondent know what use will be made of her words? Some feminist research has taken the issue further. Jewish Women in London cite instances of women who were unwilling to 'entrust(ing) their experiences to an unknown audience' (1989:16), and withdrew consent to publish. People with learning difficulties do not always know they are being interviewed for research or publication, indeed may not be told (Walmsley 1993b). Relatively few studies detail how or even if consent was sought (examples are Shah and Holmes 1987, Tymchuk and Andron 1988). Booth and Booth (1994) argue that their approach through 'key informants' allowed the person to refuse without embarrassment, though this puts an onus on the intermediary to be well informed and ethical. Atkinson and Williams' diary account of meeting intermediaries and groups of contributors graphically illustrate the messiness of the process: 'The contributors have not been prepared in advance. How much do they understand?' (1990:231).

What is noticeable, however, is that authors are at least beginning to address the issue, making transparent the dilemmas which hitherto have remained hidden, a tribute to the influence of feminists (Mies 1983, Stanley and Wise 1983, Stanley 1992, 1993b) who argue that the power relationships within the research process must be addressed honestly.

The issue of power also recurs within the research relationship around the interview. The interviewer asks the questions: the respondent is expected to answer, but as Kress and Fowler point out 'In the hands of an experienced practitioner, the devices for control granted to the interviewer by the format and situation of the

interview itself constitute a formidable armoury' (quoted in Minister 1991:29). Atkinson analyses two interview transcripts in detail, one of mine, and one of her own (Atkinson and Williams P 1990 and Atkinson 1993a), and demonstrates that the interviewer hears what she wants to hear, and elides over issues which are not part of her frame of reference. Stuart (1992) describes a moment when her interviewee turned the tables, asking 'and how was it for you, Mary?', and argues that the process of sharing personal experiences cannot be one way. Members of Pecket Well college, an independent college for disabled people and people with learning difficulties, advocate converting the interviewer into a 'writing hand' whose only job is to record the speaker's words, and check that they represent correctly what is intended (Open University, National Development Team and Living Archive Project 1994). However, this approach works to the extent of creating an individual's life story, but does not obviously extend to the interpretation of data. I discuss the dilemmas involved in this next.

#### *Ownership and data analysis*

If research is to be the product of a non exploitative partnership it is important to ask who 'owns' it. Elinor was asked to theorise from her interviews with women cleaners and balked at the request:

*The individual woman could be said to be representative, with her work, of the social relations of her position. But to theorise her, with quotations, felt like pinching her story, her clothes ... this garment of unstitched piece work would be not only unfitting but ill fitting.*  
(1992:78).

Frequently, too, the researcher approaches the work with an ideological conviction, and is reluctant to abandon it. Chappell (forthcoming) argues that it is a danger of research in learning disability informed by normalisation that definitions of normal and valued behaviour are imposed by the researcher who will re-interpret data

which does not fit, and cites the discounting of the views of Adult Training Centre users who opt for 'socially devalued' contract work rather than 'education and leisure'. Opie uses the term 'appropriation', arguing that 'feminist interpretations .. are also restrictive in the sense that they can appropriate the data to the researcher's interests so that other significant experiential elements which challenge or partially disrupt that interpretation may also be silenced' (1992:52). This remark may be applied to Gerber's critique of Edgerton's work (1967), where the words of Edgerton's informants were interpreted according to his own preconceptions about mental retardation (Gerber 1990).

Issues of ownership are exacerbated for researchers in learning disability. Traditional practices such as allowing the informants access to the tape transcripts to correct (Thompson 1988) are sometimes inappropriate because people are often unable to read and will need help in doing the task. Nor may they be able to undertake the type of negotiation described by Borland (1991) with her grandmother. The two women agreed to disagree on the interpretation of a series of interviews after lengthy discussion. Atkinson (1993b) struggled with this and resolved it by creating a book of her group's words. This became the focus of further research meetings. As she read their book to them further memories were elicited, and the final product genuinely represents a collaboration. Potts and Fido describe a similar process: 'During the three years the project has taken we have met together regularly to read aloud each chapter as it was written. Every reading has stimulated yet more memories and information.' (1991:12). Booth and Booth (1994) shared with their informants the 'life story chapters' writing and rewriting them together, though could not find a similar resolution when it came to the analysis.

In analysing information from a number of informants the researcher is uniquely placed: 'participants may occupy a less analytic and more descriptive position while

researchers may be aware of alternative interpretations' (Opie 1992:63).

Issues of ownership are at least being aired in the literature on learning disability, though are being resolved only in research which aims to articulate the details of individual lives. The type of negotiation described by Marlett (1990), Neumark (1990) and Borland (1991) to agree on interpretations of the data have not to my knowledge been tackled with people with learning difficulties.

### *Advocacy*

Some researchers resolve the dilemma of being potential exploiters of people who are already marginalised and powerless by claiming to act as advocates for their participants. Finch writes 'A feminist sociologist will of course be on the side of the women she studies' (1984b:85). Booth and Booth (1994) took the task of acting as advocates seriously, and cite instances of being asked to go to court with respondents to support them. Atkinson and Williams (1990) created an editorial advisory group to help them resolve dilemmas about how to represent people - whether to correct spelling errors, retype hand written contributions, or include 'childish' drawings. However, the practice is not as simple as Finch suggests. Patai questions the claims of feminist scholars to 'focus on the research process as an occasion for intervention and advocacy' and comments that 'in a world divided by race, ethnicity and class the purported solidarity of female identity is in many ways a fraud.' (1991:144). Gluck (1991) reflects on the conflict between scholarship and advocacy and argues that they are not always compatible. Thus although it is possible for researchers to set out to protect and promote the interests of the vulnerable people they work with, it may not be easy to do so in practice.

The dangers of research as advocacy are examined by Chappell (forthcoming) who sees in it the possibility that the values of the researcher are imposed on the views of individuals, with the consequent risk of misrepresentation. Instances of this in the literature on learning disability are not hard to find: for example there was in



the 1980s far more interest in fostering relationships with non disabled people (O'Brien and Lyle 1987, Kings Fund 1988) than there was in maintaining the relationships between people with learning difficulties. This was influenced by the values of normalisation (Chappell 1992). The consequence was that important relationships were not supported when people left hospitals and hostels (Atkinson 1986 cites examples).

### *Validity*

How far can peoples' words be trusted? Do they represent the truth? The debate on the validity of oral testimony has exercised oral historians in trying to get their discipline accepted (Thompson 1988). In contrast to empirical positivist research validity does not depend on outside verification or replicability. Instead as Sarah Matthews put it 'it is not verifiable events of the past alone that affect an individual's present, but his or her interpretation of them as well.' (1986:234). Stimson contends that 'all life histories are histories in terms of the present' (1976), thus there is no such thing as truth telling. Instead, any aspect of the product of research is significant whether or not it tallies with other versions of the truth (Dean and Foot Whyte 1978, Rosie 1993). Subjectivity is celebrated: 'Any research procedure which can tell us something about the subjective orientation of human actors has a claim to scholarly consideration.' (Blumer 1979: xxiii).

It has taken researchers in learning disability some time to accept these propositions. Seligman et al (1981) attributed their finding that people with learning difficulties acquiesced in research questions to 'deficient cognitive, verbal and social skills', though Booth, Simons and Booth speculate that the tendency to acquiescence may have been a product of the use of closed questions (1990:122-3). The solution adopted in this research, to accept what people say as important regardless of its apparent validity owes more to the feminist literature than to learning disability research. Thus the historical data has been used as a complement

to the biographical interview data, not as a means of checking validity.

Anderson and Jack discuss the significance of silences, listening for what is not discussed, and being aware of it, at the same time as honouring the lead of the narrator, and respecting privacy (1991). As an issue of validity, this can appear to be problematic, yet can also feed the interpretation. In this research I chose to accept silences as they stood, but to speculate on what areas of silence might indicate. This is in contrast to an approach which actively seeks information from other sources to complete a life story. It is a fine line.

### *The Subjective Element*

Finally I want to discuss the personal dimension, the interrelationship of the interviewer with the people being interviewed, and the impact of interviewer subjectivity. This has been touched on at several points in this Chapter already: for example, Stuart's acknowledgement of the impact her research had on her (1992); Chappell's critique of research as advocacy (forthcoming); and Atkinson's analysis of interview transcripts (Atkinson and Williams P 1990 and Atkinson 1993b). Minister discusses the impact of gender and gendered communication on the practice of oral history interviews: 'Oral history method continues to rest upon the assumption that interviewers will conduct interviews the way men conduct interviews.' (1991:31). She argues that women should interview women, a position espoused by many feminist researchers since Oakley (1981) made the case for women interviewers. However, this fails to answer a number of other discrepancies between interviewer and interviewee, particularly in this context the difference between interviewer (myself) and respondents in terms of class, disability, possibly race, and certainly educational background. With such an array of differences, common gender begins to seem insignificant!

Awareness of the self that the researcher brings to the research 'using the personal as a platform for research understanding' (Shakespeare et al 1993: 5) appears to

represent a more manageable aspiration, and one which does not deny the differences in power and opportunities to create academic 'knowledge' which inevitably exist. Stanley (1992) argues for the inclusion of the writer's 'intellectual biography' in research reports. Whilst this can become self indulgent (see for example Cotterill and Letherby 1993) acknowledging my own autobiography as part of the research endeavour appears relevant. I combined in the research several of my own personal agendas. I own to an interest in exclusion and marginalisation stemming from my own childhood sense of being different through having a Jewish father. Indeed, Jews and people with learning difficulties were both victims of eugenic purges in Nazi Germany. As a woman I have felt pushed to adopt a 'caring' role both in my personal life and in my work, and have found myself uneasily resistant to the unspoken expectations I sensed. Yet I value being a carer, feeling needed by family and friends. These are contradictions familiar from the literature on caring (Graham 1983). Finally I have long had an interest in history, in particular creating history from documentary and oral sources, and one which for some years I was unable to pursue as I put my energies into achieving a career change after child rearing. It was a challenge to weave these personal biographical interests into the research I was undertaking.

In terms of advocacy I admit to a sense of mission in uncovering the hidden history of people with learning difficulties as a means of restoring to people a sense of where they fit in the scheme of things, ambitiously, perhaps unrealistically, as a route to personal and collective empowerment. It has been argued that 'We need the past in order to be able to understand ourselves. We need it in order to believe in our future. If we have come from nowhere where are we going to?' (Hall Carpenter Archives 1989a:1). These words are from the introduction to life stories written and edited by Lesbians. While I espouse these sentiments I confess to a certain uneasiness in relation to uncovering the past of a group of which I am not a

member. For the moment it is hard to see people with learning difficulties taking on the task unaided, and there I must rest my argument.

## **Conclusion**

Research with people with learning difficulties contains echoes of many ethical dilemmas which exercise biographical researchers. Respondents are often in a position of powerlessness and ignorance which means that the researcher has to take care to monitor her own ethical stance. It emerges from this literature review that although the wider literature has influenced learning disability research, this has been largely a one way process. Bornat noticed that disabled people rarely appear in the communities of community publishing (1992:27) and it is equally true that the specific challenges of learning disability research have not been addressed by those who write about biographical or qualitative research methodologies such as Thompson on oral history (1988) and Reinharz on feminism (1992). They are perhaps the poorer for that omission.

The issues aired here are central to the arguments put forward in the thesis. I chose biographical interviews because such methods appear to have enabled people with learning difficulties to express their views, and to influence the research agenda, in particular in my own research on adulthood (1990, 1991a) and in the work of Booth and Booth (1994), (though they use the term *life story* rather than biographical interviews). Any claims that this is a straightforward process of 'giving people a voice' are, however, dubious. The issues discussed in this chapter demonstrate that representing others through research is far from simple. Despite these unresolved, perhaps unresolvable, ethical dilemmas, I proceeded to undertake the fieldwork. Chapter 4 describes this process.

## **Chapter 4: Research Method: Data Collection and Analysis**

### **Introduction**

I discussed in Chapter 3 the rationale for the choice of research method used in this research, namely biographical interviews with men and women with learning difficulties, focusing on care and caring, supplemented by research, both documentary and oral, to assist in understanding the changes in policy and practice which have occurred during the lifetimes of the research respondents.

Thus the data collection comprised two main strands:

biographical interviews with 22 men and women with learning difficulties

documentary research and oral history interviews with key informants.

In carrying out biographical interviews with people with learning difficulties research methods developed by oral historians and life history researchers were adapted to make it possible for people with learning difficulties to describe their own biographies and experiences of care. The biographical interviews were supplemented by documentary research and a small number of oral history interviews with people who were well informed about the recent history of learning disability services in the area. In view of the lack of published accounts of the history of learning disability in the locality, this historical research had the purpose of filling in the background, as well as enabling the interviewer to prompt recall, and to act as a check on validity of the interview data, as recommended by Paul Thompson in the practice of oral history (1988:197). This approach also held out the promise of enabling me to construct a social history of people with learning difficulties in Bedfordshire in the second half of the twentieth century from a combination of oral and documentary sources, an ambition that was only partially fulfilled.

The wider issues in biographical research are discussed in Chapter 3. This chapter

is written with sparing references. Those I cite act as cross references to the preceding chapter, or refer to details of the data collection.

The two sets of data collection proceeded simultaneously in the period May 1991 to October 1992. For convenience they are described separately, and where appropriate cross referencing is made; in practise the two informed one another.

The chapter is structured as follows:

- 1 The biographical interviews
  - finding respondents
  - explaining the research: making contact, describing the project, obtaining consent
  - the research relationship: involvement, power
  - the interview process
  - ownership
- 2 Documentary Research and Oral History Interviews
- 3 Data Analysis
  - factual
  - conceptual

## **1 The Biographical Interviews**

### *Finding Respondents*

At the outset I intended to locate 20 people in their forties living in the Luton area. I chose Luton because of its geographical proximity, and because I had two personal contacts there whom I could approach to assist me in finding respondents. There was no reason to believe that Luton's policy and practice in learning disability were either exceptionally good, or exceptionally poor, an assumption borne out in the course of the research. I intended to find a research population of adults with learning difficulties in a ratio of three women to one man. The rationale for confining the research to people in their forties was to find a cohort who would have experienced similar socio historical influences, which would make it possible to make links between the personal and the social. Women were to be in the

majority because of the interest in women and care-giving in the literature. An early concern was to ensure that interviewees were not hand picked by intermediaries because they were known to be givers of care. It was therefore intended to have two groups; a group who were known by intermediaries to be care givers, past or present, and a randomly selected group, located via snowballing from the original group. It was planned to hold interviews in peoples' homes as recommended by several researchers in this field (Malin, 1983, Atkinson 1989), as well as being standard advice in qualitative research (Bell and Roberts 1984, Thompson 1988 for example). Two interviews with each respondent were anticipated, with a possibility of a third if necessary. Although Atkinson (1990) found that interviews with 'natural' groups of people living in the same house were preferable to individual interviews, I anticipated that one to one was the ideal, as recommended by Thompson (1988:205).

A rough and ready criterion was adopted to include people who at any time in their lives had been in receipt of services for people with learning difficulties, a definition also adopted by Booth and Booth (1994), because it was planned to locate people in a variety of settings, not only in mainstream services for people with learning difficulties such as hospitals, hostels or Adult Training Centres. The stigma of the 'learning difficulties' label meant that advertising for respondents was unlikely to stimulate a response, even if a suitable medium could have been found.

As I began to make contacts I recorded in my research diary the matters which concerned me. I wondered whether anyone actually had any experience of care-giving, or if I would find that my hypotheses, based on some casual contacts in the past and some passing references in the literature, that people with learning difficulties are caregivers as well as dependants, would be confounded at the outset. I was aware of the possible tension between the focus on caring and the desire to obtain biographical data which may or may not have a bearing on caring. I

pondered on the best ways to present myself and how to explain the purpose of the research with a view to enabling the interviewee to refuse to participate if she or he wished. And I felt certain reservations about the ethics of asking people to cooperate when the research appeared to have little to offer them.

In the event I interviewed twenty two people ranging in age from 30 to 70 (ages and dates refer to 1992), fourteen women and eight men. I explain below the reasons for abandoning the original age cohort. The female male ratio of three to one became two to one in practice. I was able to interview people in a wide variety of living situations and with a variety of life experiences including living in institutions, group homes, with families and independently; paid jobs, voluntary work and work in institutions. The common factors were that they lived in or originated from Luton and that they were labelled as having learning difficulties. I use pseudonyms for all the respondents to ensure anonymity. More details of the respondents will be found in Appendix 1 and in Chapters Six to Nine.

A small pilot project was undertaken with five respondents initially which informed the approach. This is addressed in more detail below. The pilot interviews have been included as part of the total sample as in practice the outcome of the pilot confirmed the general principles adopted at the outset.

### *Explaining the research*

#### **Making contact**

As I was approaching the field with no individual contacts with people with learning difficulties in the Luton area, locating informants involved complex negotiations with gatekeepers. Few of my interviewees were on the telephone, and though about half can read a little I had no idea of that beforehand, nor did I know where they might read notices. A variety of strategies were adopted.

Most people taking part were contacted and briefed through intermediaries (Luton



MENCAP, Adult Training Centre (ATC) workers, social workers, nurses, adult education tutors, and friends of some respondents). This meant that I was not fully in control of the circumstances in which people were approached, and this created some problems: for example, I originally wanted to interview people in their forties, but finally extended my sampling frame to include 30 to 70 year olds because intermediaries had either forgotten the age bracket, or did not know peoples' ages. Rather than turn people away I decided to include them, and amend my planned age cohort. This meant that the population was more varied than planned in terms of age, and made some findings more tentative, an issue discussed in Chapter 10.

Relying on others to make contact also extended the amount of time required. In one instance it took six months to obtain a reply from an agency; and this yielded no interviewees. In other instances intermediaries went out of their way to be helpful; yet this may have compromised consent (see below).

### **Describing the research**

Working through intermediaries extended the chain of communication about the research. This is not an issue that has been addressed in any detail in written research reports (Walmsley 1993b), though is worth consideration for two reasons; firstly, the possibility of transmitting a distorted message; and secondly because it may make refusal more difficult (this is addressed in the next section, 'Consent').

The issues are well illustrated by examples. In one instance the research project had to be explained to five people before I got permission to interview Eileen. The original contact was an adult education tutor who referred me to the Adult Training Centre where I spoke on the phone to the receptionist, the key worker, Eileen herself (who agreed), and the Deputy Manager who in turn consulted with Eileen's family. The consent was qualified by the request that I would not address personal matters. The process reflects Eileen's status. Although an adult she was protected

both by family and by agencies. The involvement and attitude of the family seems to be the key factor, as at the same ATC another key worker introduced me to Anna, who has no family, without any formality.

After the pilot interviews I realised that an information sheet was needed as the process of explaining to intermediaries was very time consuming and somewhat erratic; there was no guarantee that the message would not go through five or six people before it reached the interviewee. Using some of the data I had obtained through the pilot interviews I drew up an illustrated information sheet which is reproduced as Figure 4.1.



The information sheet had two planned uses: firstly it gave intermediaries information about the research which they could show to potential interviewees; secondly it provided a starting point for discussion in the interview itself. It also found another unexpected use as participants could show it to other people to explain what they had been doing. One interviewee, Gary, took it away to show his mother.

The information sheet also had limitations. First of all, it may have constrained the research, giving people a set of fairly concrete ideas to respond to which may or may not have corresponded with their experiences. Secondly, it appeared, on reflection, patronising to those people who can read. Alison, for example, was critical of the way she had been approached and said that she would have preferred to respond in writing to a set of pre-set questions, rather than in a face to face interview where she had felt exposed and vulnerable. This throws an interesting light on the school of thought, associated with feminist research, which advocates free ranging interviews where the interviewee sets the research agenda (Graham 1984b, Anderson and Jack 1991). The apparently greater power of the researcher makes such assertiveness unlikely, at least initially.

### **Consent**

Consent issues are problematic as far as people with learning difficulties are concerned. The findings of Seligman et al (1981) that there is a tendency to acquiescence in answering research questions is transferable to other situations.

In approaching this research I was aware of a tension between not prejudicing outcomes, and at the same time informing people about the research to the extent that they could make an informed choice about consent. This tension was made more acute when the approach to the interviewee was made through one or more intermediaries. Alison (see above) in reflecting on why she had agreed to be interviewed said 'I didn't want to let Hazel (intermediary) down'. In using Hazel to

make contact with Alison I had unwittingly compromised her. When Alison subsequently became distressed about my initial interview with her it was Hazel who bore the brunt of her distress, not I.

At times it was not always clear that the person involved was actually consenting to be interviewed, so much as feeling she had no choice. It is a pitfall in research with people with learning difficulties that interviews for assessment and other purposes are fairly commonplace (Bercovici 1981). Atkinson furnishes some interesting insights into her interviewees' perceptions of her. One said to his social worker: 'She must be very important, asking us all these questions.' (1989:69). Consequently, when I had consulted with five people about interviewing Eileen it may have been hard for her to refuse. Whilst some authorities (see Chapter 3) regard the transaction as a contract between equals, it is hard to defend this position when the researcher suspects, as I did, that people have at best a hazy idea of what research means.

The context in which people were approached in negotiating consent was crucial, and one over which I rarely had control. This was particularly noticeable in finding interviewees in hospital. Although actually gaining access to the wards was a matter of delicate negotiation, involving a meeting with the Director of Nursing, and formal permission from the Consultant Psychiatrist, once on the ward people were presented to me with no ceremony or forewarning. None refused outright, but two of the four employed tactics which effectively sabotaged the interviews - yawning, distracting comments, grabbing my tea cup - and one of these stayed in bed rather than meet me for a second time. I can only speculate that one reason for this was the absence of any semblance of consent on their parts.

The Information Sheet was helpful as a way of preparing people for the interviews. There was no guarantee that in itself it avoided the pitfall of my being viewed as a professional service provider, but it did serve to differentiate the research from

other interview situations, and set out the contract: how many meetings, the choice of confidentiality, and the type of feedback people can expect.

However, consent issues remained problematic, especially where, as seemed to be the case, people really had very little idea of what research is, and what use it may be put to. Of the twenty two I interviewed only Alison challenged me directly beyond the polite 'you doing a project?' level of query. More typical was Isobel's response to my explanation:

*Isobel: What you want to tape it for? For the college or what?*

*Jan: I'd better tell you a bit more about myself, hadn't I. I'm from the Open University, have you heard of that?*

*Isobel: No*

*Jan: Well it's in Milton Keynes and I'm doing a sort of student project if you like. It's called research.*

*Isobel: Yeah.*

For subsequent interviews I armed myself with a copy of 'Know Me As I Am' (Atkinson and Williams 1990) as an example of what might be the product, but few people seemed enlightened by it. The practicalities of working with many people with learning disabilities are currently such that far from undertaking 'emancipatory research' as advocated by Oliver (1992), the researcher must monitor her own ethical stance. To achieve a level of understanding of research to the extent that interviewees could challenge the researcher directly was beyond the scope of this project.

Explaining the research to respondents proved problematic. Except in a few cases I am certain that people were very hazy about my intentions in interviewing them. I suspect that this is not unusual. As McCall and Simmonds observe: 'What motives, what alien causes, would lead a man to turn on his brethren with an analytic eye?'

(1969). How many people invited to take part in any research really know what is going on? Yet if research is to be a partnership it seems crucial that the aims are shared.

### *The research relationship*

Developing a relationship with interviewees is identified as a central task in feminist research (Reinharz 1992) and in learning disability research (Booth and Booth 1994). If people are to furnish details of their lives they must be persuaded to trust the researcher.

### **Involvement and rapport**

The importance of developing rapport with informants has been well documented both in research relating to learning disabilities and in qualitative research more generally (Taylor and Bogdan 1984, Jahoda, Markova and Cattermole 1989a, Cornwell and Gearing 1989). Most authorities emphasise the importance of spending time with informants, and accompanying them on their daily activities (see for example, Grant, Ramcharan and McGrath 1993, Booth and Booth 1994). This approach does have two major drawbacks, the first being that it is time-consuming, and the second that it may elicit expectations of a continuing relationship, even friendship, where that is inappropriate. Booth and Booth (1994) took on the roles not only of researchers but also of advocates and, during the field research, friends. Atkinson (1993a) found that her work with a group of older people with learning difficulties, which spanned two years, was hard to end because the group had become such an event in peoples' lives although she was careful to maintain strict boundaries of time and space.

In undertaking this research I was concerned to maintain the boundaries of a research relationship, and to confine the research activity to the interviews. This was in part a practical strategy, as the work had to be undertaken in a restricted time

period, but it reflected also an ethical position to regard people as far as possible as serious informants who do not necessarily require a paternalistic stance, unless they ask for it. In practice it was not possible to maintain this pure stance. I did observe people in situations which were not strictly research; for example, I went to tea at Anna's privately run group home, and was told about her by the owners. People talked about one another, including others in the research population. This information has not been ignored, but wherever it is used the source is identified.

Building trust did take time; the first time I met Anna I obtained little information as she asked me to play back our taped conversation seven times within fifty minutes. It was the first time she had been tape recorded. The interview ended with my promising to let her have a copy of the tape, and she insisted that I name the time I would return, despite some reluctance on my part. She made a note of it in her diary, and when I did return as agreed she rewarded me with as much information as she could recall, and her full photograph collection.

Most texts on interviewing recommend that the interviewee is seen alone: 'Nearly always it is best to be alone with an informant' (Thompson 1988:205). I found that this was not always possible, and adopted a policy of involving other people at the request of the interviewee. The first person I interviewed, Isobel, had been briefed by her Adult Education tutor in person, but was very nervous when we met, and made an excuse to end the interview after 30 minutes: 'I got to go to work soon'. However, she did hint after I'd switched off the tape that she'd like her boyfriend, Barry, there next time I came. I duly collected Barry before our next interview and the experience was entirely different, the conversation flowed, and Barry subsequently became an interviewee in his own right. He commented on his importance: 'she might feel better when I'm here, more confident' and Isobel added 'keep me company'. It may also have been an excuse for them to meet outside the Training Centre, as they live some distance from one another.



Involvement of a third person adds a new dimension to the interview. The researcher can actually observe a social relationship which casts light on the interviewee's situation. Beryl sat in on two interviews with her friend Eileen. Eventually I realised that Beryl, no less than staff and family, was determined that Eileen remain in the Adult Training Centre she's been attending for 25 years. When Eileen and I discussed the possibility of her getting an opportunity to do some volunteering work with children Beryl proffered a series of reasons why she should not: 'children can be horrible, hit you', 'your dad would be upset', 'you're better off in the Centre'. I realised how hard it was for Eileen to make any changes in her life when her friend joined the chorus of voices keeping her where she was.

It is important that the choice of companion is made by the interviewee. This was not the case with one woman who was contacted through her mother. Jacqueline was not asked directly whether she wanted her mother to be present. In the event, her mother was present at both interviews, and her mother's voice was dominant. When I gently suggested I might speak to Jacqueline alone, her mother firmly told me she would be unable to understand my questions. The findings from this interview were quite different to those where interviewees were seen alone, or with friends, something I discuss further in Chapter 6.

It is possible that rapport can mislead interviewees. Janet Finch (1984b) recounts how easy it was for her to gain the confidence of the clergy wives she interviewed. They were lonely, and welcomed the chance to talk, and may have expected a continuing friendship. Alison (see above) confided more in me than she subsequently felt was good for her, and later became quite distressed. Why this happened I can only guess, but one reason may be that as an experienced counsellor I know how to establish rapport quickly, how to stay with subjects that appear to be sensitive. Alison herself was an experienced counsellee; she knew the role well, and we may have slipped from interview mode into counselling mode.

## Power

Issues of the relatively greater power I had as a researcher by comparison to my respondents have already been mentioned. I was unsure how real consent was, for example. Here I explore the influence of power in my relationships with respondents.

I am of a higher social class than most of my interviewees, and not disabled. I was aware that this could influence the research, and that the relative powerlessness of the interviewees could distort their perception of me. It is hard to document this. One instance, however, is indicative. Lynne lives with her father, and emphasised to me how much she wanted to move into her own place. This was such a strong theme that I sensed that she perceived me as someone who could actually help her achieve such a move. It was powerful enough to persuade me to contact an acquaintance in the Social Services Department to ask whether Lynne could get any help. In a sense Lynne was right; I was powerful enough to telephone someone who could help her. Other researchers, such as Booth and Booth (1994) went much further than this, regarding it as part of their ethical obligation to act as advocates for the parents in their study.

Ethics aside, I am uncertain how problematic such power discrepancies are. As Stimson (1976) argued 'life histories will be influenced by the social situation in which they are told'. In making this statement he is drawing on a rich research tradition which includes C Wright Mills (1940) and Goffman (1959). This prompted me to view the interview data as significant for the way people chose to present themselves, rather than for factual content alone.

Within limits the interviewee can exercise some power. Anna had me switching the tape recorder on and off for her - not behaviour I had chosen. Isobel arranged for me to collect Barry and take him to her house for an interview. When we arrived she was having a personal review meeting with her social worker. Barry was

ushered in to join her and I was left sitting outside the house. I was told later that she had probably used me as a means of getting Barry to the review! In that situation she had exercised power to achieve her own goals whilst thwarting mine. These instances correspond with Stimson and Webb's findings (1993) that in doctor patient interactions the patient exercises power: to ignore the doctor's advice, to recast the story in a light favourable to them, to withhold information. The doctor, like the researcher, apparently is the one with the power; but it is not as straightforward as it appears. I was myself subjected to the power of the hospital staff in the way people were introduced, and to the power of Jacqueline's mother who prevented my seeing her daughter alone.

A facet of power was space, because it reflected the degree of control interviewees had over their environment. The question of where to meet was an unanticipated difficulty in some instances, though the advice from previous studies is to meet on the interviewees' home ground (Malin 1986, Atkinson 1989). One example is Lynne, who was approached through her work placements officer. Lynne lives with her father, but did not want him to know about the interviews. Her employer, understandably, was unwilling for us to meet at the workplace. Finally it was agreed to meet at the nearby hostel where Lynne was a familiar visitor. Similarly, Alison was living with her ex husband and his wife in a small flat. She has no workplace. We met in a Little Chef cafe, and later at my home. It was perhaps a quirk of this research, where approaches to interviewees were made in a variety of modes, that made space an issue. It has not been reported as an issue in other research projects. But not having a space of ones' own is an interesting reflection on peoples' lives and status.

### *The Interview Process*

The interviews were semi-structured. My goal was to elicit brief biographical data around key transition points - where people were born, schooled, lived in

adulthood, and with whom, the sort of work they did, and what changes they had experienced during their lifetimes. I hoped also to establish a chronology, preferably with dates. Also I planned to discuss present day relationships and activities, in particular focusing on how people saw the care/ help/ support they received from others, and what care/ help/ support they gave to others.

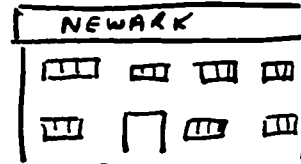
A number of techniques have been used to support research where people have limited use of language. Simons, Booth and Booth (1989) cite the use of cartoon faces - smiling to frowning - to elicit responses to items on a Likert type scale, for example. As the type of information sought in this research was more complex than expressing preferences, this was not appropriate, but in order to ensure that as far as possible people were aware of the research focus and its purpose I tried to support the research process throughout with concrete information.

After the pilot interviews, the starting point was the Information Sheet. The first interview was loosely structured, using prompts from the information sheet. After this I transcribed the tape and developed two diagrams, a 'life map' and a 'network diagram'. The life map illustrates key points in the individual's biography taken from the transcript, for example date of birth, schooling, changes of residence (see Figure 4.2).

Figure 4.2 Life Map

1943 Malcolm: born in Notts.

? family split up



1964



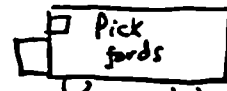
hostel

? 1965 or 1971 (about 28 years old)

Notts Forest

We are the champions

move to Luton with dad & stepmum



1971: Malcolm leaves his wheel-chair

work at



ATC

Dad and stepmum split up



July 1983

Dad died



helping people

April 1984

... moved to his flat and looks after himself



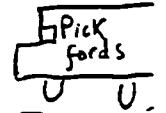
Malcolm stopped going to his Training Centre

Self Advocacy 'People First' Conference, London.

1990

'Talking Together' (hoping to move to

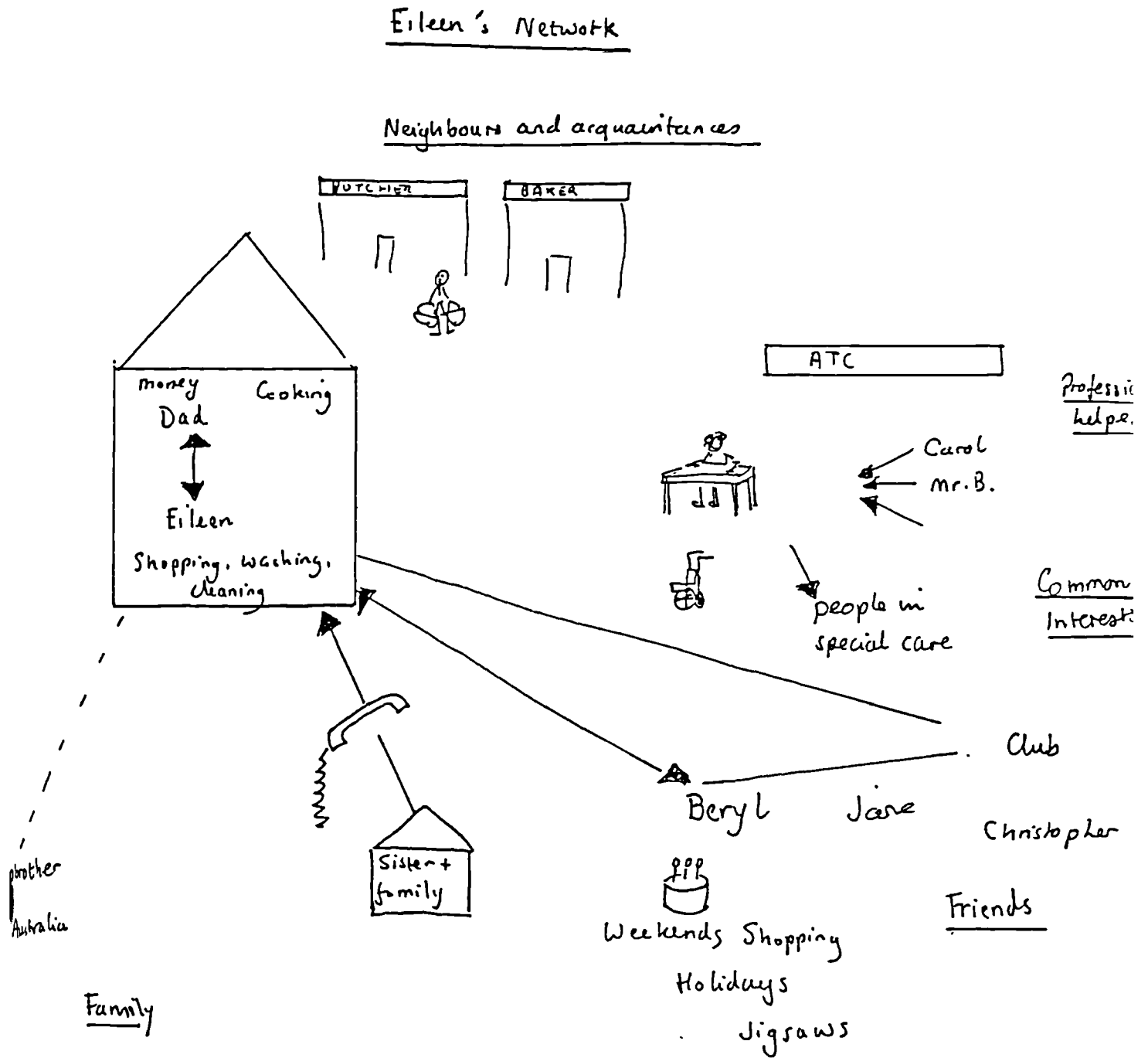
Notts



1991 Helping Raymond and his family.

The network diagram contains information about the people described as currently in the participants' social networks, with an indication of the degree of reciprocity, for example, if a relationship was indicated to me as primarily one in which the participant receives care an arrow points towards the participant, and vice versa (see Figure 4.3). Two way arrows indicate a reciprocal relationship.

Figure 4.3 Network Diagram



These 'life maps' and 'network diagrams' provided a basis for the follow up interview. I talked through the diagrams with the interviewees and any omissions, ambiguities or contradictions were pursued. The advantage of diagrams was that they could be shared with participants who could see in outline what information had been derived from their words, without too heavy reliance on the written word. I offered the diagrams to people to keep as a memento of the occasion, but they rarely accepted; I saw them very much as research tools forcing me to summarise what data I obtained in the first interview, then to revise it, and try to make sense of that data in a way that people with learning difficulties could understand.

In this way I was able to go back on points where information was unclear in the first interview, and make corrections. Peoples' inability to read once more put the onus on me to be painstaking in checking understanding; and it was valuable because it gave people the opportunity to elaborate on points touched on in the first interview. For example, Gary had glossed over the reasons for his going into hospital in our first interview, but it appeared on the 'life map'. As we went over this he explained further:

*I stayed at home for quite a long time and then I went on there (the ATC), and then I went to Bromham (hospital) for me fits. It's a long story really because where me fits are, with all the tablets I used to take, I used to take more tablets than I do now and I used to get very bad tempered and shout and swear and turn nasty so they sent me to Bromham for me medication and me tempers. I was only supposed to be there for seven weeks but I was there for quite a long time.*

An alternative to using the diagrams was to replay the tape. This was only used on one occasion, one of the final interviews, and at the insistence of Bert who was so excited to hear himself on tape he wanted to listen to it immediately. The disadvantage was that his commentary could not be taped, but his observations on

his own remarks were very moving. Mention of his mother's death prompted further memories of his experiences. (An extract from the transcript of this interview will be found in Appendix 5).

Photographs were a support, particularly when people were less articulate. If we met in peoples' own homes they showed me the photos on the walls, and talked about them. If we were in another setting I encouraged people to bring photos to our second meeting, and asked them to talk to me about who was in them, where they were when they were taken, and what was going on. Anna was quite vague about her past life, but the photos helped establish some kind of chronology, and introduced new people, like her neighbour's daughter. They also corroborated some of the things she had told me, for example the importance of her friend Helen whom she sees infrequently. There were photos of Anna and Helen smiling as they exchanged Christmas gifts, and Helen was present at Anna's birthday celebration. I compiled a little wallet of my own photographs to reciprocate if people were interested.

Concreteness was also expressed verbally. I discovered that 'care' and 'caring' are jargon words. People did not actually use them when describing relationships which involve giving and taking. Instead they use the terms 'helping' or, less often, 'looking after'. I tried to reflect this in the information sheet, following the pilot interviews. This practice, of using peoples' own terms rather than imposing language from an academic culture, is based on Glaser and Strauss's concept, 'grounded theory' (1967). As Shulamit Reinharz puts it 'the analysis draws heavily on the language of the person studied, i.e. that it is grounded' (1983:183), though later I have some observations to make on the apparent simplicity of this formula (see Chapter 8).

A final prompt was the 'story'. To end the interview relationship I compiled a brief life story based on the interview data using, as far as possible, the informants' own



words. Once more, this was usually delivered face to face as most people were unable to read it themselves. The utility of the 'story' as a means of checking accuracy varied. Eileen corrected one or two names, and the date when she left school. By contrast, Alanna used the opportunity to say what she wanted for the future:

*Jan: What about the ending? I didn't know how to end it, what about the future?*

*Alanna: I'd like mum if she lives that long to get to know me better. I don't know, I think other mothers let their daughters do what they want to do and I think I'm a bit left behind if you know what I mean, I'm doing what my mum wants me to do..*

An example of a 'story' is included as Appendix 2.

These research interviews with people with learning difficulties raised similar issues to other research relationships. All interviewers have to develop rapport, to ponder how they are perceived by the interviewee, and to check accuracy. The relative powerlessness of many people with learning difficulties and their frequent inability to read forced me to tackle those issues in a slightly different way. These may be both an enhancement and a distortion; for example, the practice in oral history is to ask the respondent to comment on the transcript, but these are bulky documents. Commenting on summaries, in various forms, or on the tape, makes the material more accessible, but reduces the power of the interviewee to amend the final record.

### **Ownership**

Much research literature recently has emphasised the importance of leaving the 'ownership' of the research with the participants: 'Recently the practice has developed, particularly amongst anthropologists, of giving a draft of the report to

research participants and asking them to comment on its validity' (Opie 1992:62). I tackled this in three ways, as described above:

- drawing up life maps and network diagrams and checking for accuracy
- summarising the research information in a 'story' about the interviewee, and reading through it with them
- working through the tape recording of the interview

I consciously omitted the normal oral history practice of returning the transcript to people (Thompson 1988:216) because the sheer weight of reading would have meant that almost all interviewees needed someone to help them go through it, and this would have compromised confidentiality. It is unfortunate that I discovered the effectiveness of playing the taped interview to the interviewee only in the final stages of interviewing, as this device appears to offer an alternative to reading the transcript for people who cannot read fluently.

The use of the 'story' has limitations as a way of giving 'ownership' to the interviewees because it is a summary and only the individual story is available. The researcher has an overview of all the interviews. The individual only knows of her own contribution and the guarantee of confidentiality requires that this remains the case. I have discussed elsewhere the difficulties of feeding back findings derived from one to one interviews to a group of research participants who know one another (Walmsley 1990). Opie identifies another difficulty: 'such a (co-authorship) relationship is difficult to achieve when participants, while constituting a community of interest, do not form a close knit physical community.' (1992:63). Some interviewees in my study do know one another, but by no means all do, and to constitute them as a group for the purpose of sharing research findings would be impractical. For instance, only one can drive a car, so complex transport arrangements would be needed. Overall, although interviewees had the final word on their own 'story', they had no means of controlling the interpretations I subsequently made of their experiences as related to me. They have had no direct

say in this chapter, for example. As Patai put it 'in an unethical world we cannot do truly ethical research' (1991:150).

A second limitation is more personal. The Jewish Women in London group comment in their introduction 'For most of the women being presented some time later with, as one of us put it, an "autobiography that they had not written" was a disturbing experience and added another dimension to the vexed question of "finding a voice"' (1989:15). Only one of the interviewees in my study, Alison, expressed reservations about having her 'story' presented to her. Because she can read I posted it to her in advance of our meeting. She described graphically the experience of reading it for the first time; having to shoo her inquisitive ex husband away when it arrived, finding a private moment, making herself a coffee, taking a deep breath, and reading it. She asked why she could not have written it herself and in the end we agreed that she rewrite it . She alone of the interviewees had the writing skills to produce such an account. The others relied on me to do so, and questioned little. The 'story' is already one step removed from the immediate interview account. It has the authority of the written word, albeit in this case mediated by a face to face meeting where I read it through to check for accuracy and approval. Perhaps it required more confidence than most people had to challenge the authority of print.

## **2 Documentary Research and Oral History Interviews**

The second major type of data collection was documentary including archival research and oral history interviews with key informants to establish what had happened in local learning disability policy, services and practice during the lifetimes of the informants. Thompson (1988) stresses that the oral historian owes a duty to informants to be well informed about the background before undertaking interviews. Thus prompts can be used where appropriate. However, there were other reasons for trying to flesh out the historical context. The local history of

learning disability is not well known, particularly to the people who receive the services. Without informing myself I was unable to understand the context of people's life experiences, or understand passing references made to places and people. My rather immodest ambition was to write the history of those services combining insights from both oral and documentary research, something partially achieved in Chapter 5.

Secondary printed sources were few, and all written by administrators or professional social workers. I found a copy of Tomlinson's *Investigation of Problem Families in Luton* (1946), a publication sponsored by the Eugenics Society, and one of several local studies of its type (Philp and Timms 1957). I found one booklet entitled *The History of the Mental Health Services in Bedfordshire 1948 to 1970* (French 1971), written by the then Deputy Director of Social Services and a former Mental Welfare Officer. I was also able to interview him, making him one of my four oral history interviewees. Other material was available in local libraries which made brief reference to mental handicap services, for example Dony's *History of Education in Luton* (1970), Monk's *History of Fairfield Hospital* (1960) and *Services for the Mentally Handicapped* (1967), a brochure produced for parents by Bedfordshire County Council, Luton County Borough and Bedford Borough Council. These sources afforded a basic outline of what services were available, when set up and who they catered for.

In order to supplement these sources, I undertook further lines of enquiry, research into the records of the Bedfordshire Mental Deficiency and Mental Health sub Committees in the County Record Office (see Appendix 3 for details of these sources): examination of the *Year Books* of the *Luton Society for Parents of Backward Children*, later *MENCAP*, from 1959 to 1992; and interviews with four people who were in a position to recall details of the recent past; Rene Harris, a parent and founder member of the Luton Society for Backward Children, later

MENCAP; Cecil French, author of the *History of the Mental Health Services* and former Mental Welfare Officer; the Director of Nursing at Bromham Hospital; and a former nurse at the same hospital. The latter wishes to remain anonymous.

The archives were rich in detail for the period 1914 to 1960. No effort had been made to conceal names or places; though the printed minutes used initials, not full names, the presence of all the Clerk's correspondence and the Deputy Medical Officer of Health's reports means that individuals can be readily identified. After the introduction of the 1959 Mental Health Act the records become more sparse with only the formal papers of the Mental Health and Mental Treatment sub Committees being retained. Access to documents after 1972 was embargoed under the 20 year rule. This meant that information on the later period was most readily accessed from other sources, oral and printed.

In the event, the written historical sources provided detailed information on how people with learning difficulties have been treated in Bedfordshire in the period 1913 to 1959. These were, however, a total contrast to the biographical accounts, and the major points of cross reference were where by chance I found the names of my informants in the records of the Mental Health sub committee, invariably in the context of their being certificated as 'mental defectives'. At no point did these contradict what people told me in the interviews, but interviewees used very different language. For example, Isobel told me: 'I was grown up and I was about 14, I was a pretty girl, then I went to Bromham and used to look after the doctor's children'. The official account was 'Examined by Dr. Harvey. Isobel M D age 13, 102 H- Road Luton. Notified by Medical Superintendent, Three Counties Hospital. Institutional care' (Report from Deputy County Medical Officer of Health to Clerk to Mental Health Treatment sub committee dated 27/2/58 in Beds County Record Office He/sub P 6/3/1).

What distinguished the oral history interviews from the biographical interviews

with adults with learning difficulties was the purpose of the enquiry. I set out to interview these people for factual information about the way learning disability services had developed, rather than for their own life stories. In the event the interviews with the male professionals were distanced from individual biographies. The interview with Cecil French, for example, tallied with his written account in French (1971). The one interviewee who acted as a bridge between the worlds of the interviewees and the official domain was Rene Harris, both a parent, and, in a voluntary capacity, a service provider. Whilst I had approached her for historical information, the interviews with her were also of biographical interest. She had known many of my interviewees personally over many years and her memories corroborated and expanded upon some of their accounts. I give three transcript extracts to illustrate these three dimensions;

Historical;

*'Um well the Occupation Centre wasn't the first facility. The first facility was the Home Teacher, Mrs. Bewes, the mother of the famous actor.'*

Personal biographical;

*'In the meantime the education authorities had decided my child should be excluded from school. Ineducable. It's a terrible blow. Well it must be a terrible blow to anybody but when you've had a reasonable education and set store by what you were going to do for your children to learn that one is ineducable is very hard to take.'*

Personal links with interviewees;

*(of Barry) 'No he never went to school because they wouldn't have him at (the local school) because he wasn't clean and he had tantrums, and because his mother didn't have enough about her to*

*find out what she could do he didn't do anything till Mrs. M (home teacher) came on the scene'. (Interviews held August and October 1991).*

The oral history interviews provided insight into different ways people experienced historical events partly according to their roles. Rene Harris and Cecil French described the same events around the creation of Adult Training Centres, but whilst Rene presented parental pressure as being a deciding factor in the decision to build a new and larger Training Centre in 1959, Cecil insisted that this was the result of the untimely death of the home teacher, and the difficulty of recruiting a replacement. These differences in interpretation are explored more fully in Chapter 5.

A key point in the limited cross references between the biographical interview data and the historical material was identified in Chapter 3. People do not necessarily see their lives as primarily framed by being labelled as having a learning difficulty as the research by Bogdan and Taylor (1976) and Atkinson and Williams (1990) shows. I may have been accessing the wrong history from their point of view.

(Details of the sources consulted are in Appendix 3).

### **3 Data Analysis**

The data analysis fell into two distinct categories, factual and conceptual. The two were concurrent, but for convenience I describe them separately.

#### *Factual information*

The purpose of analysing the data for factual information was twofold: first to obtain an overall picture of individual lives, and second to build a collective picture of 22 lives and to establish a typical life course (Humphrey 1993) of the lives of people with learning difficulties in South Bedfordshire. It was my intention to create a 'history from below' (Williams and Walmsley 1990). To some extent I saw

myself as interviewing 'for history' (Bornat 1992:84), that is, I was hoping to elicit the views of the people I interviewed on the historical changes they had experienced as users of learning disability services.

Analysis of the interview data for factual information began at an early stage, through the devices of life maps and network drawings. These were essentially tools which I used to establish some basic biographical information, and to identify gaps, contradictions or confusions arising from the first interview. Concurrently, the archive research, and oral history interviews threw light on some of the experiences people described to me, for example Barry said 'I went to school on Tuesdays in the Youth Club in S\_\_ Road', and I was able to establish from the historical research that he was referring to sessions held by the home teacher in the village hall in the mid fifties. Thus the veracity of his evidence was established from another source, but his particular phrasing, that he went to *school*, has an interest in its own right.

As the historical research proceeded I established a basic chronology of when services were set up, and their nature. I tried to use this knowledge 'for history'. For example, having been told by my nurse informant about the practice of giving patients a bath on a weekly rota basis, I asked Gary about this:

*Jan: Cos I was talking to a nurse in Bromham and he said you only had a bath once a week. Is that right?*

*Gary: Something like that, yeah. What was his name?*

*Jan: Keith.*

*Gary: Oh yeah, I think he must have done 5b. Did he have glasses?*

This interchange was a not untypical result of such efforts to prompt reminiscence. Gary was more interested in people than institutional practices, and made a number of attempts during our interviews to establish some common acquaintances. This



was one of them. I discovered that although knowledge of the context enabled me to explain to myself some information that my interviewees assumed I already knew, I could not thereby persuade people to share my own interest in history. If people wanted me to know more, they told me. If they did not, my informed prompts did not change their minds. As Bornat observes 'deliberate choices and decisions on the part of the interviewee may be shaping the content and direction of the interview' (1993:93).

A final observation on the extent to which I could make use of the life maps to construct a historical argument about cohort differences is that there was great variation in the amount of data obtained. Some 'life maps' were complete with dates and key events. Others were sketchy in the extreme (Appendix 1 demonstrates the disparity in the amount and nature of information different interviewees supplied). I constructed a master date chart, with all the life map data entered, to search for patterns, but there were too many gaps. My solution was to choose one interviewee from each of the four decades represented to stand as a representative, rather than to use all the interviewees for this purpose. The result is Chapter 7, 'Representative Lives', in which I present four 'auto/biographies' to enable the reader to consider the interaction between historical time and individual life experiences, drawing on themes derived from the historical element of the research. In doing this I consciously imposed a conventional chronology on the interview data, a practice which reflects my own purpose, not the interviewee's choice. Extracts from the relevant interviews are included as Appendix 5 so that the impact my authorship has had on the text is visible (Stanley 1992).

My conclusion following this process is that interviewing individuals 'for history' in the way I did, without giving them a sense of that purpose, was inappropriate and unprofitable. The work of Potts and Fido (1991) and Atkinson (1993a) was an inspiration, but their work was with groups and, as Atkinson describes, her group

gained a momentum of its own once a publication, called 'Our Book', showed people what the outcome might be. Without that clear commitment I was unable to prompt extensive reminiscences, and the full collective history from below is postponed.

A further task for the analysis of factual data was to create links between what interviewees said and the evidence from the historical research. I have commented above on the use I made of this element of the research to understand what I was told in the interviews. A deeper level of analysis was furnished by identifying assumptions made by the interviewees which were reflected in the historical data. The most salient of these was the significance of families as a source of accommodation and 'care' well into adult life. Services were based on the family as the bedrock of care, and the interviewees tacitly accepted this as a feature of their own lives. Even in the absence of family, the potential role of the family was acknowledged.

There was a consistent tension in the research between the oral history purpose of the interview data and its role in generating perspectives on care and caring, a dual purpose described by Bornat (1993). As a result of analysing the data and writing the thesis the role of the biographical data became primarily a tool for understanding peoples' relationships. As historical data it remains in a state of 'notes towards a history', and as an insight into contrasting accounts of similar events.

### *Conceptual Analysis*

*The goal of grounded theorising is to facilitate more rigorous definition of categories through the process of analysis rather than specifying what categories are appropriate and how these are to be defined at the beginning of the research process as in hypothesis testing research (Boulton and Hammersley 1993:21).*

There were initially two central tasks in conceptual analysis: establishing how people described care and caring, and identifying gender differences. However, as the quotation above states, specifying relevant categories at the outset was only part of the data analysis task. I tried to be open to new links, 'to learn to listen in a new way, to hold in abeyance the theories that told me what to hear and how to interpret what these women had to say' (Anderson and Jack 1991:18). Thus the final product explores more areas than I had anticipated at the outset, and poses new questions.

In principle I followed Glaser and Strauss (1967), attempting to ground the concepts in the language and assumptions of the interviewees, and to identify categories. This took some time, and involved a number of false starts.

In relation to how people talked about care and caring it emerged from the pilot interviews that these terms were not used. Instead, people talked about 'looking after' and 'helping' when describing what went on in relationships. In order to pin down the meanings of these terms I gathered together a small group at the Training Centre to establish what precisely they understood by 'caring', 'looking after' and 'helping'. Although I used primarily one to one or one to two interviews, it is noteworthy that discussion in a group was fruitful in drawing out a sense of shared meanings, something the individual interviews did less well. The outcomes of the discussion are described in Chapter 8, and assisted me in differentiating nuances of meaning in relation to the way care and dependence within relationships were described.

A second major finding was that people only talked about issues relating to care and dependency within specific relationships, not as abstractions. This enabled me to move from my initial analysis based on roles - mother, daughter, friend, etc. - to creating categories of relationships - with family, friends, staff - as a way of structuring a discussion of how people talked about care and dependency. In retrospect it seems obvious that people would place care and caring within specific

personal relationships, rather than talk of them as abstractions, but is an indication of the importance of grounding the discussion in the terms interviewees used, rather than basing it on the abstractions found in most of the literature reviewed in Chapter 2. These findings are presented in Chapter 8.

I found that grounding the discussion in the language used by interviewees was not always possible. This was particularly the case where people described negative experiences within care relationships. By contrast to the 'helping'/ 'looking after' framework which was almost universal, it was not possible to identify any equivalents to describe controlling or neglectful behaviour, either done by or done unto people. Such experiences were sometimes described through stories - for example Gary said of his boarding school:

*The school where I was at they were horrible people. If you said anything out of line they'd put you in a sleeping bag and tie you to the bed. (Interview GM 1992)*

I suspect these more negative experiences of caring were also the subject of silences. In order to include these I created categories using terms I imposed. Again, these are presented in Chapter 8.

A further dimension of data analysis emerged in relation to gender issues. Whereas I began by looking for gender differences exclusively, repeated examination of the interview transcripts showed that there were similarities as well as differences in the way men and women presented themselves and their lives. Thus two important dimensions of identity relating to being labelled and work emerged from most of the interviews, but gender differences were insignificant. By contrast, most men differed from most women in their narrative styles, men tending to present themselves as making choices while women seemed to perceive themselves as relatively powerless to dictate what happened to them. These issues are discussed in Chapter 9.

The process of analysing the data threw up questions which were not anticipated at the outset; in particular Chapter 9 is the product of my discovering in the interview data information on being labelled, on work and on personal identity. Having discovered these areas I systematically trawled the transcripts for relevant material.

### **Conclusion**

The findings of the research emerged from consistent readings and re-readings of the data, data which itself was the product of an interaction between two or more people in a specific relationship at a particular time and place (Stanley 1992, Bornat 1993). Analysis of unstructured data can be directed towards different outcomes. This analysis was directed by my twin interests in biographies and their interaction with historical events, and by the focus on how people described care and caring, and by implication how they experienced these within their past and present relationships. The focus remained throughout; but the outcomes were influenced by a complex interaction between my research questions and what I actually read and heard. Stanley (1992) points to the importance of recognising that data is the creation of an interaction between the researcher and her text. Doubtless a different researcher with a different set of interests could have produced different results from a similar set of data.

## **Chapter 5: Learning Disability in Luton: 1946 to 1992**

### **Introduction and Rationale**

This chapter describes the social context in terms of learning disability ideology and policy during the lifetimes of the interviewees. In Chapter 2 I described the ideological and policy changes in learning disability which led to people being seen as a 'dependent group', in particular within the family. This chapter fleshes out that account in the local context of Luton and South Bedfordshire. As for most of the period Luton was administratively part of the county of Bedfordshire the sources drawn on are county wide, and the county's policies and practices dictated what happened to Luton residents. I draw together information from documentary research and oral history interviews described in Section 2 of Chapter 4 to examine the development of care relationships, both familial and statutory, and how they were mediated by gender. I also make some links with the experiences of adults with learning difficulties as relayed to me in the biographical interviews.

The task of constructing this local study has been made more challenging because of the absence of an up to date history of learning disability in the late 20th century. Jones' standard text (1972) is now over 20 years old and has been criticised for its whiggish optimism (Williams and Walmsley 1990), and though there is some useful material on ideological changes (Ayer and Alaszewski 1984, Alaszewski and Ong 1991) and on hospitals (Morris 1969, Alaszewski 1986, Ryan and Thomas 1987), and Stainton's four articles are a useful summary (1991, 1992a,b,c) these do not set out to be comprehensive histories. Nor is there any detailed research on gender, though Thomson (1992) has made a start on the inter war years. It is therefore hard to see whether the local experience was significantly different to the national norm.

The chapter is written as if the reader is familiar with the main legislative and policy changes. These are summarised for reference in Appendix 4. See Appendix 3

for details of the sources.

The decision about whether to use real names has been a difficult one. It is necessary to identify the location of the study; otherwise the local sources would be unverifiable. I use real names of places, as anyone who knows the county's learning disability services will know the names of the Hospital and the ATC. With permission, I have also identified Rene Harris and Cecil French by their real names as their former public positions would make hiding their identities pointless. However, I have used initials instead of surnames in the documentary extracts, and continue to use pseudonyms for the names of the interviewees with learning difficulties as I do elsewhere. There is the possibility of compromising confidentiality if any reader were to pursue the detailed references to individuals in the documentary sources. This is a risk which seems unavoidable if the normal conventions of referencing are to be followed.

The detailed description begins in 1946, when a Mental Health Service was set up. The post World War Two era covers the lifetimes of all but three interviewees. But certain themes are recurrent, and some background information is included on the period before 1946.

### **The Background: Development of Services 1913-46**

Bedfordshire was initially slow in implementation of the 1913 Mental Deficiency Act. In 1926 its ascertainment figure of 0.57 per 1000 was low compared to a national average of 1.46 per 1,000 (Letter from Board of Control) to Clerk to the Bedfordshire Mental Deficiency Committee dated 30/10/26), and in that year there were 17 people under supervision, visited by a sole voluntary visitor, and 67 in institutions. In the same year Somerset had 1,131 people under supervision, and 399 in institutions (Board of Control Annual Report 1926). In 1937 Bedfordshire was fifth from bottom in the Board of Control's league table of ascertainment rates whilst Somerset was fourth from top (Board of Control Annual Report 1937).

Bedfordshire was slow in developing its own institutions for 'mental defectives'. There was no colony until Bromham House was licensed for 12 'high grade employable males' in 1931, though it grew rapidly to house 194 men and women in 1938. No Occupation Centres were created before World War Two, though Jones reports that these were fairly numerous nationally (she cites 99 in 1927 1972:214), and correspondence between the Board of Control and the Bedfordshire Mental Deficiency Committee in 1938 indicates that the local authority were under pressure to make some provision (MDL4). Perhaps most significantly, there were no paid specialists for 'community care' other than the Clerk to the Bedfordshire Mental Deficiency Committee and the Deputy Medical Officer of Health (Deputy County Medical Officer of Health) responsible for ascertainment and certification. A Mental Deficiency Officer was appointed in 1939, but she was called up for war service and did not take up the job fully until 1945 (MDL4).

The reasons for Bedfordshire's slow early response are not obvious. Thomson (1992) discusses factors influencing geographical variations in ascertainment rates and local provision for mental deficiency in the inter war years, and summarises these as a combination of socio-economic factors, such as unemployment which reduced the family's capacity to provide care; the presence of local activists, especially women volunteers; the attitudes of local poor law authorities; and religion. He could find no simple correlation between party political orientation and the level of provision (Chapter 6).

Some of these factors appear to be relevant to Bedfordshire (and Luton, its largest town). Luton is not noted for its public welfare services. Bunker, Holgate and Nichols write: 'For much of Luton's history, the care of the poor and the sick rested on a combination of self reliance, philanthropy and minimal public support' (1993:109) and describe the workhouse as 'dismal' (1993:112). Initially Poor Law Boards of Guardians resisted requests from the Bedford Mental Deficiency



Committee for information on defectives within their jurisdictions. For example, a letter from Leighton Buzzard Union dated 6/3/1915 states: 'There are several persons mentally defective in the Bedfordshire parishes of the Leighton Buzzard Union, but it is not considered necessary that any of them be dealt with under the Mental Deficiency Act as they are all well and properly cared for and may satisfactorily be dealt with by relief being advanced by the Guardians as heretofore' (MDP1). Unlike Somerset (Atkinson forthcoming) or London (Thomson 1992) there were no specialist wards for mental defectives in the County workhouses prior to 1913. I found little evidence that there were numerous local activists as there were in Birmingham in the inter war years (Barker 1993). Only two names regularly appear in the Bedfordshire Mental Deficiency Committee records, both of whom were Voluntary Visitors for defectives under supervision at home.

Part of the motivation for lack of provision was probably reluctance to incur expenditure. The Clerk reminded the Bromham House Joint Board when expansion was under discussion that consideration should be given to 'the needs of the fit at whose cost they must be supported' (1938: Joint Board Papers 4). I found no indication that there were ideological objections to the Act's philosophy that mental defectives were a danger to themselves and the community, though Bedfordshire refused to support the campaign for sterilisation launched by Southampton in 1938 (MDP4). Given the county's strong liberal nonconformist political traditions (Godber 1969) it is unsurprising that sterilisation was not favoured.

The numbers of people certified under the 1913 Act increased rapidly after Bromham was set up. There were 150 in institutions and 37 under community supervision in 1937. By 1947 these figures were 387 and 138 respectively (He/sub P 6/2). This suggests that the existence of professionals and a colony prompted greater activity, despite accommodation and labour problems during the War.

*The experiences of families and 'defectives': care and gender*

For the majority of people, care meant family care. The belief that mental defect was inherited meant that families were subject to surveillance, particularly those which failed to conform to middle class standards of morality and cleanliness as I show below. But the system set up under the 1913 Act consistently reinforced the responsibility families had to their defective offspring. Even when the authority decided to send a person to an institution the family had to contribute to maintenance costs. In Bedfordshire a good deal of the Clerk's correspondence relates to the collection of arrears (MDC 1-40 passim).

The responsibility for supervision of defectives under statutory supervision in their own homes fell to the voluntary organisation, the Bedfordshire branch of the Association for the Mentally Defective which was paid sixty pounds a year by the Bedfordshire Mental Deficiency Committee in 1937-8 (MDP 23). Insight into the way family care operated is given in the quarterly reports prepared for the Bedford Mental Deficiency Committee by Miss Mumford, Voluntary Visitor for the local branch of the Association for the Mentally Defective. In 1937 she visited 56 adults and children quarterly. Most of her comments appear benevolent; 'Olive S, aged 26 in good health, well cared for by her grandmother.' Girls' and women's domestic contributions were noted with approval 'In spite of the girl's paralysis it is wonderful the amount of tasks she can perform in the house and she helps her grandmother all she can.' She was able to request small amounts of financial help for families, which the Committee invariably agreed to, on condition that she supervised the expenditure. She also had the function of singling out the 'undeserving', for example the S family 'The home is a poor one, although there does not appear to be a lack of money. Mother is a delicate person of very simple intellect'. Their daughter Hilda was later that year taken into institutional care, and it continued to be described as an 'unfortunate family' (all references in this

paragraph from MDP 23).

Deservingness and ability to control the behaviour, in particular the sexual activity, of the defective were consistently used to decide on how defectives and their families were treated. The standard form (issued by the Board of Control in 1929) used by the Visitor or the Deputy County Medical Officer of Health to report on the homes of defectives included the question 'Is it considered that the control available would suffice to prevent the defective from procreating children?'. If the home was deemed 'good' the Deputy County Medical Officer of Health was always inclined to leave the defective in the care of the family. Samuel E, aged 17, visited by the Deputy County Medical Officer of Health in Feb. 1937, was left at home, uncertified: 'As he comes from a good home, though he is easily led and below average intelligence, I prefer at present to consider him a borderline case' (MDP 23). Olive B, aged 13, visited in the same month, was recommended for institutional care; the Deputy County Medical Officer of Health wrote: 'the home surroundings are definitely bad, with a history of mental trouble in the father, and a very simple minded mother'. In this case the family were keen for institutional care (MDP 23).

Those who were sent to institutions were almost invariably far from home, until Bromham began to grow in the late 1930s. Cell Barnes, Hertfordshire, Stoke Park, Bristol, and Whittington Hall, Staffordshire, were favoured by the Bedfordshire Mental Deficiency Committee. Once their relatives were sent to institutions there was little contact, and the Clerk's correspondence includes some plaintive letters from families; one mother wrote: 'my son has been away now from home since 1917: a life time really and there seems no hope of his ever coming home' (1940:MDP26). Leave was granted only after minute investigation of the family's ability to control the defective's movements and a home visit by local authority officials (JBV14 1/2).

Families could and did impede the authorities' decisions. Unwillingness to see their child sent to an institution was reported frequently. In 1932 Bedfordshire Mental Deficiency Committee claimed that the reason 15 of 32 children reported by Luton Education Committee as defective were still at home was that the parents refused to agree to institutional care (MDP23). Parental resistance was overridden at times, in particular where an adolescent girl was deemed out of control, or when a boy was delinquent. For instance, Grace H of Luton, aged 16, was institutionalised in 1938, despite family objections, after staying out all night and keeping 'bad company' (MDP23 *passim*).

Sexual regulation of young women appears to have been a consistent policy, most evident in wartime. Detailed analysis of a sample of 35 new cases reported to the Bedford Mental Deficiency Committee in 1916-18 shows that women were in the majority (22), and that 11 of these were accused of sexual misdemeanours, actual or potential. All 11 were sent to institutions. Males were more likely to be certified in childhood or early adolescence (11 of 13), while only 6 women were under 16 when certified (MDP3). This bears out Thomson's findings that women were targeted in late adolescence, and that sexual misdemeanours were a major reason for certification of women (1992:224; see also Rafter 1983 on the incarceration of sexually deviant women as 'feeble minded' in the USA).

Having employment, or the prospect of obtaining it, was a factor in peoples' favour when certification was considered, but was no proof against certification where a young woman's morals were in question. Florence B was employed at the Luton and Dunstable Hospital earning 25s per week when she was found to be feeble-minded and in need of institutional care after attending a VD clinic (MDC41, 1940).

Women were not only institutionalised for sexual misbehaviour, there were also attempts to regulate behaviour through employment. Within institutions there was

an expectation that patients would be economically productive 'a workshop wherein much useful work can be effected for the Local Authority' (Medical Superintendent's Annual Report on Bromham Colony 1943). Jobs were gender specific. In Bromham in 1943, according to the Board of Control inspectors, 87 per cent of the patients were 'employed'. Men worked in farm, garden or wards, or in trades such as mat making and cobbling. Women were ward maids, domestics, or worked in the sewing room, kitchen and laundry. It was policy that no women worked outside the Colony, although some men were employed on local farms (Board of Control Annual Report on Bromham Colony 1943). Women were not encouraged to develop skills other than domestic skills; the same was not true of men who, it appears, were encouraged to find outside work, and become skilled in trades.

Good behaviour was a key to being released from institutions on licence. Patients were allowed out if relatives were willing to accept responsibility, and were deemed suitable, or to approved employment. For women this employment was invariably in domestic situations which could exercise control over their lifestyle. In 1940, 10 women were out on license from Bromham, all of whom were either in domestic service in homes approved by the authorities or in hospitals and similar residential institutions. They were paid between 7s 6d and 10s a week (for comparison it will be remembered that Florence B was earning 25s a week for similar work before she was certified). For men, farm colonies, such as Tubwell Farm in East Sussex, were the only similar regulated employment (MDC41 passim). But some men were able to obtain positions which gave them independence. George O, released on licence to a relative in Birmingham in 1937, found work in a rope works earning 35s per week, and eventually entered military service (JBV14 2; 1937-39). The use of domestic work as a means of controlling women, and encouraging them into approved womanly behaviour, is reminiscent of

Rafter's findings in research on the women's reformatory movement (1983).

### *Summary*

This brief overview of the working of the Mental Deficiency services in Bedfordshire before 1946 shows that, despite eugenic beliefs that families were a source of corruption, they were in practice the main means of caring. However, little practical support was available to them. It also provides confirmation of the view that control of deviant female sexuality was a significant motivating factor as Thomson (1992) argues in the context of London, even in a county where zeal for implementation of the Act was unremarkable. All those reported to the Bedfordshire Mental Deficiency Committee were liable to be judged on moral grounds. Homes, attitudes, intellect, appearance were described in detail in the Reports of the Voluntary Visitor and the Deputy County Medical Officer of Health. Some families passed muster, and were either left in peace or supported financially and morally by the Visitor and the Committee. But those which did not were subject to scrutiny and regulation, and harassment if they did not comply with official judgements. Ultimately the Local Authority had the power to remove 'defectives' and incarcerate them for a lifetime with no right of appeal. This power was most often used, even abused, to regulate the sexual behaviour of young women; and once in the institution those women were expected to engage in domestic work, a role which had the dual function of cheap labour and inculcation of approved female behaviour.

### **Ideological continuity: the 1940s**

'In the post war era little change occurred in the basic structure forged in the eugenic fire' (Stainton 1992a:20)

The incorporation of the Mental Deficiency Colonies into the National Health Service in 1946-8 is an administrative landmark, but had little immediate impact on

beliefs about mental deficiency. The family continued to be viewed as a potential source of corruption.

This continuity is demonstrated locally by the publication of *Families in Trouble: an Enquiry into Problem Families in Luton* in 1946 by Charles G Tomlinson, Senior Administrative Officer in the Public Health Department in Luton. It was one of five such enquiries sponsored by the Eugenics Society (Philp and Timms 1957). It seems likely that Luton was favoured because the then Medical Officer of Health, Fred Grundy, was a prominent member of the Eugenics Society (Blacker nd, c 1952).

Tomlinson defined 'Problem Families' as those who were 'unfortunate or feckless' and who needed a 'disproportionate amount of care and supervision' (1946:3). In the foreword Grundy referred to 'a growing demand, based on sheer self defence, for more extensive powers to aid and control the few who cannot and will not discipline themselves'. Not unexpectedly, the findings seem much influenced by eugenic ideas. For example, Tomlinson found that in 97 of the 167 problem families identified in Luton 'subnormal mental capacity' 'appeared to be characteristic of one or both parents' (p.29). He wrote: 'Conclusive evidence of genetic defect as the main cause of social problem families cannot arise out of a survey of this kind, but in the case of one eighth of the families there is strong prima facie evidence of inherent disposition to social inadequacy as the only cause' (p.33). He concludes that rehabilitation and education are needed and ends with a discussion of the possibilities of creating local services for problem families - health visitors, nursery schools and Pacifist Service Units along lines pioneered in Manchester and Liverpool, staffed by prototype social workers. The book's publication coincided almost exactly with the appointment of mental health workers, following the reorganisation of the mental deficiency services in the wake of the National Health Service Act, and the growth of community facilities (Jones

1972). Eugenics was not dead, but it had forged an alliance with Fabianism (Ray 1983, Williams 1989).

The book gives an insight into views about mental deficiency present in the local administration, though it is hard to say how widespread such views were. The idea that there were 'problem families', usually working class, was not new (Philp and Timms 1957, McNicol 1987). There are instances of the use of the term by the Bedfordshire Mental Deficiency Committee and its officials pre war, & the similar 'unfortunate family' was used to describe the S family in 1938 (see above). Rene Harris (parent) seemed aware of the concept when she said of Kirby Road Occupation Centre:

*I wouldn't say that there were very many middle class children there, not very many, the majority were I think from feeble minded parents*

She illustrated this with an example:

*His mother, she's a dear little soul, but she's practically illiterate. His father was a long term hospital patient in Fairfield (Psychiatric Hospital) (interview RH 1991).*

Cecil French (Mental Welfare Officer 1947-1966) was dismissive of any link between 'problem families' and subnormality (as he termed it):

*Problem families as such were not our headache ..something that struck me particularly was that any suggestion that subnormality was linked to social class was an absolute fallacy (interview CF 1992).*

The continuing moral panic about the dangers posed by defectives is illustrated in a memo from the Mental Treatment sub Committee (successor to Bedfordshire Mental Deficiency Committee) dated 1949, asking the North West



Metropolitan Regional Hospital Board (responsible for Bedfordshire's hospitals) to provide more institutional places 'in view of the fact that the presence of certain mental defectives in the community is a danger to the mental health of parents and the physical welfare of members of the community' (He sub m 6/1). This is the first time I found family welfare used as an argument for more provision, a recurrent theme in the post war era.

Unsurprisingly, given the stigma associated with mental deficiency, some parents chose to hide the fact that they had a handicapped child. Cecil French recalled:

*There were quite a number of people who were as it were kept quiet, kept in a back room and it was not at all uncommon for, if something happened to elderly father and mother all of a sudden somebody came out of the woodwork, kept in an upstairs room (interview CF 1992).*

Rene Harris also recalls that people hid their 'backward' children.

*I mean people were inclined before there was so much publicity to hide the fact that they'd got a child...Mrs. R never let on to the outside world that she'd got this mongol child. If he didn't go out in the car he was kept in the garden. Nobody knew of his existence..There would be plenty of people like that (interview RH 1991)*

This evidence supports Stainton's argument (1992a) that in the late 40s and early 50s when the majority of the interviewees were born, the climate was highly stigmatising for families with backward or defective children. Not only did they have the defective child, they also lived with the perception of hereditary and contagious defect emanating from themselves and their offspring, with the possibility that their child would be 'put away'.

*The Growth of Services: 1946 to 1966*

The post war years saw a growth in the number and variety of services provided. Prefiguring care in the community (Bayley 1973) there is evidence that the facilities were seen as an adjunct to family care, making it possible for families to continue to provide for mental defectives, though Cecil French in his interview (1992) emphasised that services always lagged behind perceived need.

In 1948, with the inception of the National Health Service, it was decided that a comprehensive Mental Health Service should be established in Bedfordshire (French 1971:2). The Mental Deficiency Committee handed over to the Mental Health sub Committee (sometimes referred to also as the Mental Treatment sub Committee), and a scheme was drawn up to be submitted to the Minister of Health. This scheme was minimal. Four non medical mental health visitors were to be appointed and two occupation centres were to be set up, one in Bedford and the other in Luton. The scheme drew general approval from the Ministry, but they queried whether four officers were enough to maintain a 24 hour service for defectives in the community, and emphasised the need for trained personnel. By contrast neighbouring Hertfordshire had 928 certified defectives in 1948, and planned to open both occupation centres and industrial centres in each of seven main towns (He sub p1).

The most immediate benefits of the new National Health Service to families were financial. The requirement to make maintenance payments for institutional care disappeared and from 1948 Public Assistance was available to families in financial need. Hitherto, payments to families were made only after minute investigation by the Bedfordshire Mental Deficiency Committee. This removed at least some of the surveillance and moral judgement to which families had been subject, though the Local Authority continued to make payments to some parents who were formal guardians to mental defectives, on the grounds that these parents

were reluctant to take state aid (He Sub P/1: 1947).

### **Ascertainment and Certification**

The establishment of a Mental Health Service coincided with a further increase in the number of certified defectives, from 638 in 1946 to 799 in 1957 - 451 males and 358 females in institutions or under statutory supervision plus 28 males and 29 females under 'friendly supervision' (He sub P 6/3/1). 'Friendly supervision' was a new concept in the county though had long been advocated by the Central Association for Mental Defectives in letters to the Bedfordshire Mental Deficiency Committee pre war (1916:MDP1). It was intended for borderline cases. Bert, one of my interviewees, was subject to 'friendly supervision' after leaving school in 1955 (He sub P 6/3/2).

Reasons for certification show elements of continuity from pre war years. The 1944 Education Act had made it a duty of local authorities to report to the mental deficiency authority any child who 'is suffering from disability of mind to such an extent as to make him incapable of receiving education at school, or is mentally disabled in such a manner that it is inexpedient that he should be educated at school' (He sub P/1). This made it difficult for children to escape certification. The majority of 'cases' reported were children, usually of school age, or immediately after completing school.

Social class remained an important factor in decisions to certificate. PG, aged 4, was visited by the Deputy County Medical Officer of Health in 1948. He reported: 'The mother feels very resentful that any question of mental deficiency should have been raised. The home is a very good one and I would recommend that no further action is taken.' Families needing financial assistance opened themselves to scrutiny. BR's father died in 1947. His mother was certified blind. She applied for Public Assistance, and this resulted in her son, aged 46, being certified as 'feeble minded', enabling her to become his guardian and obtain maintenance (He sub

P6/3/1).

Young women who were sexually active continued to draw the attention of the authorities. PH aged 16 was put on probation because she was said to be in 'moral danger'. When she did not comply with the terms of the probation order she was examined, found to be 'feeble minded' and sent to Ashton House, Cheshire. The Committee approved the action post hoc (He sub P6/3/1).

Another major factor was availability of family. AK aged 45 was certified as 'feeble minded' in 1947 after her mother died and her sister found her too great a responsibility. BP aged 38, was certified as an idiot in 1948 after being reported by a health visitor. Her mother was too old to provide care and attention, and she was recommended for institutional care (He sub P6/3/1).

The National Council for Civil Liberties campaign of the early 50s highlighted the infringement of civil liberties which the operation of the Mental Deficiency Acts made only too likely (NCCL 1951, Stainton 1992a). The evidence from Bedfordshire corroborates the National Council for Civil Liberties' claims. The Mental Health committee was increasingly a rubber stamp for the decisions of its officials. After 1948 Place of Safety Orders could be used to detain people without parental consent or a judicial order. JS discharged herself from the Three Counties Asylum in 1951, and was immediately detained under a Place of Safety order, and sent to Leavesden hospital. She was pregnant, and 'could not receive the necessary care and supervision at home' (He sub P6/3/1).

Discharge from the provisions of the Act remained difficult. In 1949 four people were discharged: three who had held jobs for 10 years or more, and one woman engaged to a 'stable Vauxhall worker' (Deputy County Medical Officer of Health Report). The reluctance to discharge hospital patients was attributable in part to the need for patient labour (DHSS 1957). It also appears to be a result of professional complacency. In March 1956 it was reported to the Committee that only two

children had been re-assessed as ESN since 1948. 'It reflects the great care and skill which is used in ascertainment' (He sub P 6/3/2). When BR's mother died in 1960, after the 1959 Act came into operation, a Mental Welfare Officer was appointed his guardian because 'although properly classified as a defective the patient has in fact for many years cared for his mother' (He sub P6/3/2). This example shows that some so-called defectives were acting as caregivers and demonstrates the irony of providing 'care' for them.

### **Ideologies emphasising caring and support to families**

There were clear shifts in official attitudes to mental deficiency from the early 1950s. Family care was always in practice the bedrock of the system, but care and support for families rather than control and stigmatisation came to characterise policy rhetoric too. The earliest signs of this are to be seen in the County Medical Officer's Report to the Mental Treatment sub Committee in 1949. Parental distress was quoted as evidence of the shortage of institutional accommodation; a Doctor was quoted as saying 'It is a truly pitiable case and the mother is in danger of becoming a mental wreck herself'; and an almoner that 'the mother is very much at the end of her tether' (He sub P 6/2). The conclusion was that to care for families more hospital places were needed.

Stainton sees the mobilisation of parent pressure groups as evidence that stigma was being overcome (1992a:21). Change began with the parents of school age children. The Luton branch of the National Society for Parents of Backward Children (my emphasis)(later the National Society for Mentally Handicapped Children, and later still MENCAP) was founded in 1955. Rene Harris said this was set up by a group of parents whose children had been labelled as 'ineducable'. She described her reaction to this:

*I still have that very hurtful letter. Ineducable. It's a terrible blow. I tried to fight it but I knew we didn't have a leg to stand on because I*

*knew that he was very backward (interview RH 1991).*

Rene's experience shows that there was little support or information for parents and the early years of the Society are characterised by a single minded determination to provide services for the many who were uncatered for (Luton Society for Parents of Backward Children Year Books 1960 to 1969, henceforward referred to as *Luton Society Year Books*), and this coincided with pressure from professionals to extend their own scope.

Cecil French describes himself waging an eternal battle for resources on behalf of families: 'As far as subnormals were concerned we had between us 350 to 400 so they were very fortunate if they got two visits a year.' (interview CF 1992). In practice, 'supervision' was less frequent than the formal requirement of quarterly visits. Rene Harris said they would have welcomed more visits (interview RH 1992), and Mrs. M, Jacqueline's mother, said the visits were the only source of support and advice from professionals (interview JM 1991). From 1949 the use of 'respite care' for short periods begins to be recorded (He sub P 6/2).

The changing climate begins to be evident in the language used to describe people. Parents tended to describe their offspring as children - adults are referred to as 'boys' and 'girls', the provision of a family atmosphere is valued. Rene put it neatly: 'our little people they're like children, they do relate to someone who's always there.' (interview RH 1991). This is echoed elsewhere. In June 1951 a member of the Mental Treatment sub Committee wrote after visiting Kirby Road 'those in charge would appear to be giving everything they have unceasingly for the poor little afflicted souls committed to their charge' (He Sub P 6/2). This 'eternal child' model was evident in the way services were created and run. Its impact was also evident in the commentaries several respondents made in the biographical interviews. Alanna, for example, commented that what she wanted for the future was for her mum to recognise her as an adult: 'I think I'm a bit left behind .. I'm

doing what mum wants me to do' (interview AL 1992). The continued residence of many people I interviewed with parents well into adult life also points to a prolonged childhood or adolescence (see Chapter 6).

### **Day care: 1946 to 1966**

The earliest community services were developed for children. In the immediate post war years Luton was no exception to the rule that Special Education Services were patchy and rarely met the pre World War One hopes of providing a comprehensive system of special provision for physically and mentally handicapped children (Hurt 1988:154-5). In 1946 the only facility in Luton offering special education was the School at Osborne Road with 62 children (Tomlinson 1946), set up under the *Elementary Education (Defective and Epileptic Children) Act 1914* (Dony 1970). By 1964 in contrast there were 181 ESN children in day education in Luton, plus 22 in residential schools, as well as others in categories such as 'maladjusted', 'delicate', 'epileptic' (Luton Education Committee 1968).

Osborne Road School served only those children who were judged by the LEA to be 'educable'. In 1946 ineducable children, and all adults, had only hospital as an option to family care. Beryl, for example, born in 1932, never went anywhere as a child (interview BE 1991). Provision for children excluded from school began in 1947 with the establishment at Turvey of an Occupation Centre, serving Bedford. In 1948 a second Occupation Centre was opened in an old egg packing factory at Kirby Road, Dunstable. Three of the interviewees went to Kirby Road. There was also a home teacher who visited 'ineducable' children in their homes, and set up weekly classes in rural areas (interview RH 1991). Barry attended one of these classes in his village (interview BS 1992).

Not everyone went to the new Occupation Centres. This was partly because of poor information to parents. Rene says she heard about Kirby Road by chance. She was, she said, 'at a low ebb' and 'opened her heart' to a woman she met on a park

bench: 'She said "I know there is another place, I don't know where it is, but I know there is another place because the coach comes round and picks up those poor little souls"'. She got a place for Derek. But Mrs. M (interviewee's mother) had to wait until her daughter was 8 before getting a place. Mrs. M. indicated in her interview (1991) that she wanted a place earlier, but there were no spaces. However, both Rene Harris and Cecil French referred in their interviews to parents hiding their children (see above) and this may well have had a bearing on the continued underestimate of need.

Reports on the Occupation Centres display a new interest in education rather than containment. There was a clear modelling on schools - the same holiday dates and school dinner prices, for example, and the same coach contractors transported children as were used by the LEA, until ambulances took over in 1952 (He sub P 6/3/1). The Board of Control's regular inspection reports use terms such as 'curriculum', 'class', and the inspectors looked for evidence that there were progressive schemes of work, more than keeping the children occupied to pass the time. Kirby Road drew consistent praise from the inspectors for its curriculum and skilled staff, though in 1953 they commented on overcrowding, and the coming need for 'an adult class'. The motto was 'Happiness First, All Else Follows' (Luton Society Year Book 1980). According to Mrs. M its attraction was primarily social; 'Course they all wanted to go to the place. There were nothing there really. You see they were together, somewhere to go' (interview JM 1991). The similarities with school, and perhaps a sense of shame, may explain Lynne's insistence that she went to *school* at Ridgway Avenue, Kirby Road's successor, in her interview (1992), and Barry's reference to his class run by the home teacher as a school which operated only on Tuesdays (interview BS 1992).

The provision of Occupation Centres proved to be a good investment if the intention was to promote cheap family care rather than expanding hospital



provision. All the first group of 16 children considered for admission to Kirby Road were on the waiting list for hospital care. Within six months of the opening of the Centre all the names had been removed from the hospital waiting list, at the request of parents (French 1971:3). In 1948 there were 36 children awaiting institutional care (He sub P 6/2). In April 1957 there were no children on the waiting list, and only one adult (He sub P 6/3/1). This suggests that even low levels of support to families paid off in terms of minimising expenditure on hospital places, but it is also probable that it enabled the authorities to prioritise what they saw as urgent cases. In 1954 Shirley D aged 18 was found to be making 'undesirable associations' whilst attending Dunstable Occupation Centre, and was sent to an institution (Minutes of April 1954 Mental Health sub committee He Sub P 6/3/1). Unfortunately, from 1951 the Deputy County Medical Officer of Health reports are not archived with the Mental Health sub Committee papers, so such details are rare. Most people I interviewed were born in the period when these community facilities were being set up, as the median age in 1992 was 43. Some, like Isobel, did go into hospital in their youth (interview 1991 and He Sub P 6/3/1). Others, like Barry, were intended for institutional care (the Deputy County Medical Officer of Health report states 'institutional care, supervision pending accommodation being secured', 20/1/1950 He sub P 6/2), but never went. Instead he received the services of the home teacher. Thus changes of policy, as well as personal circumstances, influenced the course of their lives.

The development of community services, though inadequate, was clear indication that rather than being seen as a menace to be controlled, most children with mental handicaps were increasingly viewed by the Mental Health Services as dependants who needed care, and their families as needing support in providing that care. But it was also pragmatic. There were never enough hospital places for everyone, and, as well as financial constraints, there was local political resistance to expanding them.

In 1948 a local councillor articulated fears that Bromham's expansion would create the largest concentration of mental defectives in the country (He sub P 6/2).

### **Community Services for Adults**

Services for adults were slower to appear, with the result that the old regime continued. Four adults from the P family were admitted to Cell Barnes and Bromham after their mother died, though all had paid employment (April 1954 Minutes of Mental Health sub committee He sub p 6/3/1). Adults were not officially catered for in Kirby Road, though many, like Shirley D, stayed on beyond the school leaving age because there was nowhere to go. The need for more community facilities was noted in the October 1954 minutes of the Mental Health sub committee. Seventy adult defectives in the community were identified who would benefit from 'home teaching' or a place in an Occupation Centre. Pressure began to be exerted by the Mental Welfare officers for such facilities. In October 1955 one argued that they 'can in fact be regarded as one means of preventing mental ill health' (He sub P 6 3/1). It is worth noting that the educational mode was assumed to be appropriate for adults too.

In 1959 a new centre to replace Kirby Road was commissioned, Ridgway Avenue (French 1971). There was the familiar difference in interpretations between Rene Harris and Cecil French over the reasons for its establishment. Rene Harris regards this as a result of parent pressure:

*The attitude of the authorities was that they had never been to school, some of them were 30-35 years of age and that they couldn't go to that place because they were too old (interview RH 1991).*

Cecil French disagreed. His version was that they could not recruit a home teacher when the existing one was killed in a car crash and the only alternative was a training centre (interview CF 1991). The demand soon outstripped the places

offered at Ridgway Avenue, and Bramingham Adult Training centre was opened in 1966, specifically for adults.

### **Bramingham ATC**

For the first time all adults could expect day 'care'. Twelve of the interviewees had been to Bramingham Centre. At the time it opened it was regarded as 'a dynamic enterprise' using all the latest 'modern methods' (Luton Society Year Book 1967). The description in the Year Book gives an opportunity to view in microcosm the discourses informing its establishment. On the one hand it had some of the trappings of a school with one room designated as a 'classroom'. On the other hand it was a workplace with a subcontract workroom, carpentry shop, garden plots and a laundry, reminiscent of Bromham in the 1940s. It had a domestic training room. Activities for men and women were clearly differentiated: 'The carpentry shop where boys (sic) are introduced to tools and given an awareness of danger'; 'the domestic training room where the curriculum (sic) states that groups of girls shall cook themselves a meal, wash clothes and do simple mending and ironing, shopping and budgeting.' The use of the terms 'boys' and 'girls' is in keeping with the idea that the Centre caters for eternal children, but sits ill with its purpose as a precursor for outside employment, though this too was alluded to: 'the laundry can be considered a pre employment area'. Even at this stage the message is that it is unlikely that the 'boys' and 'girls' will leave to get jobs:

*The world of outside industry can be a strange and forbidding place for the mentally handicapped person. Not only is he likely to be alarmed by the swifter pace and new faces, but the controlled environment and understanding he has been accustomed to may well be absent. (Luton Society Year Book 1967:29).*

The emphasis on domestic activities for girls is a further element of continuity from pre-war practice, though couched in different ideological terms. These are now

children, not dangerous sexual beings.

Regarding employment outside the Centre, even the modest optimism attending the opening was misplaced. By 1971 the laundry had become a source of cheap labour, undertaking all the laundry for the Social Service Department (Luton Society Year Book 1972). This marks a major change from an ostensibly training establishment to a workplace in its own right. The ATC became for the majority of its users a career in itself, to be followed five days a week until retirement. According to Beryl, only Lynne had successfully made the transition to paid work (interview BE 1991). There are echoes of the hospital career for life.

Bramingham's importance in the lives of more than half the interviewees makes its confused messages particularly poignant. Its role of caring for people who would find the outside world harsh and uncaring complemented the traditional desire, articulated by the Wood Committee, that defectives should be economically productive (1929). For the first 20 years of its existence Bramingham undertook a good deal of contract work. Since 1988 such contract work has been officially discouraged and there is now very little: 'Programmes of training are decreasingly dominated by work experience and now have a commensurately greater input of education (in the broadest sense of the word).' (Beds JCC 1988: Para 3.5.20). The education mode has at present emerged as the dominant strand in the ATC, though this was regretted by several interviewees who valued having a job of work to do (see Ch. 9), and regarded the education offered as irrelevant. As Beryl said, 'I know how to cook. What use gardening? I haven't got a garden' (interview BE 1991).

The message emerging from the interviews was that the most compelling reason to go, as had been the case for Kirby Road, was that it was somewhere to be together. For parents its respite care function was underlined in 1993 when it was proposed to introduce a four day week. The parents objected so strenuously that the proposal was withdrawn and residents of the local hostel were kept at home instead (Beds

Herald and Post 7/4/93).

### **Residential care**

Before Bromham Hospital was founded, institutional care was used by the Local Authority as a place of last resort, for people who had nowhere else to go, or for those whose families were judged to be unsuitable to care adequately for them. The growth of Bromham meant institutional care could be offered more readily, but the messages are more benign. Hospital care began to be described as something to assist families, and to provide 'treatment' - 'Our colony has been well reported on by the Board of Control for the environment, being that of a large country house, is considered by medical men to be so helpful in the treatment' wrote the Clerk to the Bedfordshire Mental Deficiency Committee to a complaining father (1940: MDC41).

The hospital remained until 1971 the only form of residential care. Formally it became seen as an adjunct to family care. Cecil French stated he had no option but to seek admission to Hospital if the family could not cope with their 'defective' child at home 'because in those days there literally was nothing apart from the hospital' (interview CF 1991).

In November 1947 there were 280 patients in Bromham Hospital (Board of Control Annual Report 1947 in He sub P 6/1), and substantial waiting lists. It was, apparently, a period of optimistic expansion. In the early 1950s plans were drawn up to provide for 1,000 beds, and some increase did take place. However, the Minutes of the Mental Health sub Committee suggest that the North West Metropolitan Hospital Board, responsible for Bedfordshire's hospitals was unwilling to pay for more places (14/1/49) and in 1948 at least one local councillor was sounding alarm bells about expansion: 'it will lead to the first link in a chain which would lead to Bromham House becoming the headquarters and the biggest colony of mentally deficient people in the whole country' (He sub P 6/2).

Bromham specialised in 'high grades', though some high grade men had been rehoused in a ward in Fairfield Psychiatric Hospital after the War . 'Difficult' cases were sent to Leavesden Hospital which could be made secure. Others went to Cell Barnes and Harperbury, or further afield if places could be found (interview CF 1991). This had long lasting effects. In 1986-7 there were still 70 Bedfordshire people living in hospitals other than Bromham, of whom 45 were outside the county (Beds JCC 1988). In contrast, Anna, one of the interviewees, comes from Bristol, but found herself in Bromham Hospital.

In line with national trends (Stainton 1992a) Bromham hospital continued to expand until the late sixties when it had 480 residents (interview with Director of Nursing at Bromham 1992). During that period its nature changed. In the immediate post war years many of the patients continued to work productively. Charles Francis recalled that both Bromham and Fairfield Hospitals had their own farms: 'they grew their own cereals, they had their own pigs, they had their own herds, it was completely self contained' (interview CF 1991). In the 1949 Board of Control Annual Report reference is made to 15 'girls' in daily employment in the laundry, and 13 in the sewing room. However, the glittering picture of a self contained productive colony painted in the 40s became tarnished. The 1958 Annual Report of the Bedfordshire Hospitals Group bemoaned the loss of high grade patients.

*The policy of discharging suitable patients on licence whenever possible has continued with perhaps added impetus recently, depriving the hospital of many willing hands capable of useful employment. Tasks undertaken by patients must now be undertaken by staff and it has become necessary to augment the establishment.*

(Bedfordshire Hospitals Group 1958)

This is illustrated by the increase in laundry workers from one full and two part

time in 1948 (Board of Control Annual Report 1948) to 16 full time in 1958. The 1958 Report notes 'until recently women patients were engaged in laundry work'. As often appears to be the case, this official Report exaggerates the decline in patient labour. Isobel worked in the laundry at Bromham after her admission in 1957 (interview ID 1991) and Gary continued to work there as an ex patient in 1992 (interview GM 1992).

Cecil French was not critical of hospitals as such, but aware that people were sent into hospital who otherwise could have lived relatively comfortably in the community:

*I would suggest that we had no alternative, if the family could not cope, we had no alternative but the hospital. They might well have been capable had accommodation been available, suitable accommodation and suitable employment or day care it could well have been possible for those people to live in a hostel and go out to a workshop or whatever, I'm quite sure of that (interview CF 1991).*

His view is corroborated by the admission of working adults when parents became ill or died. I referred earlier to the admission of four adults living in Luton to Cell Barnes and Bromham Hospitals in 1954, after their mother died, despite all being in open employment (He sub P 6/3/1). Arthur, one of the interviewees for the fieldwork, also had this experience. He worked as a hod carrier with his father. When his father died he was admitted to Hospital (date unspecified: interview AG 1992).

The hospital provides the clearest illustration of the care/control dichotomy in the 50s and 60s. The 1967 Luton Society Year Book contains an article entitled 'Bromham Hospital and Community Centre' by A. Chalmers Fleming, the Medical Director of the Hospital. 'We care for the mentally subnormal' he proclaims. The Hospital's chief aims include training, both educational and social, nursing care,

physical and mental development, healing, research and maintenance of community links. He wrote:

*At Bromham we prepare patients to return to the community..it is the place where the actors learn their lines. If they forget them or have not been taught them, they must learn such lines properly. The "lines" are the art of independent living (p.10).*

Ironically, this pronouncement was just prior to the Ely Enquiry (DHSS 1969), and Morris's *Put Away* (1969), events which precipitated a continuing disillusionment with hospital care.

Views of both parents and residents belie the benign image. For parents the hospital was a place to be dreaded. Rene gave the parents' view:

*I'm sure people didn't want them to go. There was just no other alternative, especially when they were becoming adult .. throughout the 1950s and 1960s the one fear of my parents was that their child would have to go to Bromham. They couldn't bear the thought of it. I tried hard to persuade them that it wasn't a fearful place, it was quite marvellous in those days (interview RH 1991)*

Rene's son went to Bromham when he was 17, in 1958. Rene described her feelings:

*It is a very hard decision. I should think for 18 months after the decision I cried myself to sleep. I felt like a murderess. I really felt that I'd condemned him to death. And that was really when I drew myself into MENCAP heart and soul. I thought you know I must fight for all those who are in the community because perhaps those parents won't have to undergo this trauma (interview RH 1992).*

Rene displayed considerable ambivalence about Bromham as a home for her son.



Although she says he was happy at Bromham, she recognised that he had gained in skills and confidence since he had left: 'He improved beyond belief when he came out, he was very much more aware and making himself understood' (interview RH 1991).

The reminiscences of interviewees are mixed. Isobel described it as a 'prison', and dwelt in particular on the injustices of nurses and sexual control (interview ID 1991, see Chapter 8). Jane, another interviewee who had experienced hospital refused to talk about it, beyond saying it was 'horrible' (interview JJ 1992). But Gary said he made friends there, and was happy (interview GM 1992). Despite a closure programme due to be complete by 1996 it was still official policy in 1988 to admit people 'on social grounds alone' (Beds JCC 1988), and two interviewees, Mike and Bert, were admitted or readmitted during the period of this research.

The shift to voluntary rather than compulsory treatment, with legal safeguards provided by Mental Health Review Tribunals in the 1959 Mental Health Act (Jones 1972) made little immediate difference. Hospital admissions continued to outstrip discharge, as the increasing numbers until the late 60s demonstrate. As late as 1988 the Bedfordshire Health Joint Consultative Committee acknowledged that 'Bromham is a 'home for life' for a majority of the residents' (Beds JCC 1988:7).

While the rhetoric of training and preparation for a life outside was the public face of the hospital, it has remained an institution which can be used for control as well as care.

### **Residential facilities in the community**

The creation of residential facilities was given impetus by the 1971 White Paper *Better Services for the Mentally Handicapped* (HMSO:1971), as an alternative to increasingly discredited hospital care. It can also be seen as a further adjunct to family care. Community residential philosophy continues the twin themes of

familism and gender differentiation visible in the ATC.

The development of residential facilities in Bedfordshire was slow, but not exceptionally so. Whereas some local authorities had developed hostels and half way houses in the 1930s (Jones 1972), only 43 of the 227 Local Authorities in England and Wales provided them in 1969 (Alaszewski 1986). The first hostel opened in Luton in 1971. Perhaps unsurprisingly, its establishment was the subject of great interest on the part of the Luton Society and appears to have been modelled on the MENCAP Model Hostel, Sheltered Workshop and Training Centre at Slough. The Slough experiment demonstrates the twin themes of care in a family atmosphere and economic productivity which characterise the development of services in the third quarter of the twentieth century. The 1960 Luton Society Year Book refers to 'an attempt to demonstrate the capacity of the mentally handicapped to produce goods at marketable value'. There were 'two families of 15 severely handicapped young men and women .. each group has its own house parents' (Luton Society Year Book 1966). Slough's influence on the conceptualisation of residential hostels in Luton is evident. Writing in the 1967 Year Book Ron Ward extols the virtues of hostels:

*The girls and boys would, I feel sure, benefit by being separated from their parents..Each hostel could have their own foster parents who would be responsible for the children's health and welfare. Very special care in choosing the right foster parents would be required..The girls could be taught to cook under supervision, and made responsible for all meals at the hostel..the boys should be encouraged to make outside excursions: perhaps going to the cinema or a football match. (Luton Society Year Book 1967:49-50)*

The extension of familial ideology to this new setting, and continuing private/public dimension in the gender roles envisaged is notable. Ward also

advocated the siting of the hostel near the Training Centre, for ease of access to the workplace (Luton Society Year Book 1967:50).

Wauluds hostel, opened in 1971, bears a remarkable resemblance to Ward's vision. It was run by a married couple, Mr. and Mrs. Hill, who were seen in a quasi parental role. A letter to the 1972 Year Book refers to the 'Wauluds House family'. Rene Harris said: 'I really do think our children need a family atmosphere..I liked it very much when Mr. and Mrs. Hill were in charge.' The account of the hostel's opening in the 1972 Year Book refers to 'boys' and 'girls', though the place was indubitably for adults. Comment is made on the readiness of the girls to make their rooms homely 'with their wigs, dolls, radios and the like' while the boys were apparently slower to settle in. The hostel was sited near Bramingham, fulfilling the ideal of a nearby day centre. The twin poles of the hostel and the ATC ghettoised people with learning difficulties in the north of Luton where the majority of the interviewees lived at the time of the fieldwork.

However, evidence from the interviewees in this study suggests that the hostel was primarily used for the people who would otherwise have been in hospital, or for those discharged from hospital into the 'community'. Contrary to Ward's vision of its being an alternative for families to choose instead of home based care, only one of the 22 interviewees (Mike) went into the hostel straight from home whilst his parents were still alive (interview MD 1992). The others who were offered hostel places went there from hospital (interviews ID 1991, JJ 1992, AF 1992). Rene's son also went to the hostel after leaving Bromham. It remained the case, as it had for most of the century, that families who could provide a home which passed muster were not offered alternatives until ill health or death forced the issue.

Residential facilities are today more diverse, including group homes and private homes. Familial ideology continues to inform their development: 'Residential accommodation will be provided such that no more than ordinarily sized family

groups will live under the same roof' (Beds JCC 1988:4). The need for a 'home like' environment is repeated in the document, including within the hospital. The Bedfordshire Strategic Plan 1988-94 refers to the 'daily stress and anxiety' of carers as a reason for providing more services, an implication that they are intended to support family care (Beds JCC 1988:1). My own study of group home residents in Luton (Walmsley 1992) suggests, however, that this is largely rhetorical. All but one of 18 residents of four group homes were ex hospital residents, not people who had family homes available.

Policy documents after the 1960s do not mention gender, and formally there appears to be no recognition of the fact that people with learning difficulties are gendered. 'Moral danger' had been superseded by terms such as behaviour disorders or challenging behaviour (Beds JCC 1988; *passim*). Nevertheless, gender did appear to influence policy and practice. Of my interviewees only two of the fourteen women had their domestic needs catered for by staff, whereas seven of the eight men did. Barry, the only man I interviewed who attended the ATC was also the only ATC user who came and went as he pleased (personal observation and conversations with staff 1991-2). Whereas this may be a coincidence, it suggests that, as in Bromham in the 1940s, men were granted more freedom of movement outside institutions than women. Similar gender differences applied to work and to sexual relationships, issues I take up in Chapter 9. A major difference between modern practices and attitudes and those prevalent until the early fifties is that then these gender distinctions were overtly policy; in 1992 policy appeared to be gender neutral.

## **Conclusion**

Family care has always been in practice the mainstay of services. Even in the pre-war era when families were officially stigmatised, they provided the bulk of 'care' for people. The requirement that families continue to pay maintenance for those in

institutions is formal evidence of this. In the post war era professionals discovered that supplementing family care was cost effective, though the growth in hospital admissions to the late 1960s demonstrates the limitations of the model, and the relative weakness of mental handicap pressure groups - parents and professionals - in wresting resources away from hospitals and the Local Authority.

Professional and parent viewpoints did not always coincide, but there appears to have been a consensus that care was best provided in families, and, where this was not possible, familial and educational models borrowed from children's services were, at least rhetorically, the preferred option. However, lip service was paid both by hospitals and day care to 'training' for an adult life. Consonant with the image of people as children in the post war era is the disappearance of references to overt control of sexuality and morals from official sources. From the mid 1950s the image of people as a eugenic danger vanishes from sources such as the Minutes of the Mental Health sub Committee. However, this did not end the confinement of people - it merely made this confinement appear to be for their own good, rather than that of the community. The replacement of the image of the defective as menace with the mentally handicapped person as an unfortunate childlike being requiring benign care and protection in practice reinforced family models of care. Services were seen as an important, if always inadequate adjunct. People continue to be regarded as the subjects of care, and their potential as productive members of society either lost, or, as in the case of those people who worked in institutions, out on licence, or in their own homes as carers, disregarded. The local study reinforces the messages of the literature review - that people with learning difficulties need carers, and productive roles they may have as caregivers or workers are ignored, or redefined.

The voices of people with learning difficulties are absent from the deliberations and debates about services. Their voices and views go unrecorded, except as mediated

by professionals, volunteers and family members. Hence the importance of research such as this which uncovers a hidden perspective on the past, and shows how adults with learning difficulties perceive and experience the policies and practices which shape their lives.

It is against this background that the life experiences of the interviewees, and the way they describe themselves, must be viewed. In particular, in the chapters that follow, I show that the way services have been structured, eugenic beliefs about sexual activity and procreation, the assumptions about the naturalness of family care, and the construction of people as dependants has influenced both their life experiences and their views of themselves.

## **Chapter 6: Introducing the Interviewees in context**

### **Introduction**

This chapter introduces the interviewees, describes their living circumstances, daytime and leisure activities, and their networks of relationships. In it I show that they shared with many people with learning difficulties restricted social networks (Atkinson 1986), unemployment (Jenkins 1991) and financial dependence (Davis, Murray and Flynn 1993). The chapter also discusses relationships in terms of independence, dependence and interdependence, concepts which were introduced in the literature review (Chapter 2). This provides a background to the more detailed discussion of the way care and caring were talked about by the interviewees, Chapter 8. I also discuss two interlocking themes from Chapter 5: the significance of family, and the influence of local learning disability services on individual lives.

The data on which this chapter is based derives from interview data, personal observation during the fieldwork and some information given unsolicited by others I encountered whilst undertaking the fieldwork - mainly people through whom I made contact with the interviewees. In this respect it differs slightly from the following chapters (7,8,9) which are drawn solely from interview data. In writing this chapter I acknowledge that I have created an account of the lives of the interviewees which they may not recognise. I have imposed on a set of individual and idiosyncratic accounts an apparent coherence in order to demonstrate links with the existing literature, and to analyse peoples' lives within frameworks of, for example, social class and dependency, which did not emerge directly from the interviews. This violates some of the principles of biographical research discussed in Chapter 3 that the interviewees' own words must speak for themselves (Bogdan and Taylor 1976, for example), and that the analysis is grounded in the language people use (Glaser and Strauss 1967). If it is justifiable it is so because 22 individual accounts do not speak for themselves unedited. But it is this chapter

which caused me most difficulty in writing.

In this chapter, and all subsequent ones, personal names have been changed to pseudonyms to protect the identity of the interviewees and the people they mention. Most other names, of places and projects, are retained in their original forms, except where they might lead to identification of individuals. In cases where changes have been made I use italics. The quotations are not individually referenced. In all cases, except where indicated, they are from interview transcripts.

The development of local learning disability services was outlined in Chapter 5. There I argued that services were tailored to supplement the ideal of family care. At the time of the interviews (1991-2) some services were changing substantially, prompted mainly by the impending closure of Bromham Hospital in 1996. To summarise, the principal day time service was Bramingham Adult Training Centre. Group Homes run by voluntary and private organisations were being established, principally for people coming out of Bromham Hospital, but they were also catering for people like Isobel and Anna who had left hospital years earlier, had lived in Wauluds Hostel and were being moved on to make space for more dependent people in Wauluds. There were still about 200 people living in Bromham in 1992 (interview: Director of Nursing, Bromham Hospital 1992). The people for whom least was changing were those who lived with family or alone, and the continuing Bromham residents.

### **The interviewees**

I introduced some of the interviewees in Chapter 4. Appendix 1 lists each person alphabetically with brief biographical details. The interviews took place in Luton or in Bromham Hospital in 1991 and 1992. Most interviewees had been born in Luton, and spent their lives in Bedfordshire. All of those who weren't natives of Luton were living there at that time. As described in Chapter 4 I used a broad definition of 'learning difficulties', namely people in receipt of specialist services for people



with learning difficulties at some time in their lives, including special schools as well as adult services. This means that several interviewees, notably the mothers, were not actually using specialist services at the time of the research, though all these people did describe themselves either as having learning difficulties or as 'backward'. I made no attempt to categorise the interviewees on the basis of their degree of disability, or on other medical criteria, and these are mentioned only when the individual referred to a particular condition, for example Gary's epilepsy. However, all interviewees had some speech, and would therefore be unlikely to be categorised as having severe or profound learning difficulties.

The 22 interviewees ranged in age from 70 to 30 (all ages and dates refer to 1992). The average and median age was 43. There were 14 women and eight men. All but one of the group is white, the exception being Stella who is black. She told me her father was from Jamaica.

Social class was not a focus of the research. Nevertheless, an impression of the class background of the interviewees will help the reader picture peoples' circumstances. Determining the social class of disabled people is complicated by prolonged residence within the family, poor employment prospects, and by the failure of mainstream sociological studies on class to consider disability (Jenkins 1991). In this study no one talked about class, and the discussion is based on employment status of the interviewee, father, where known, and, in one case, husband. From the point of view of employment (or lack of it), all but two interviewees was in social class E using the Registrar General's Classification. The two exceptions were Lynne who had an unskilled manual job, and Sheila, who was married to a quarry worker (both social class D). Only two of the interviewees were, or had been, married, both to men with manual jobs. If social class is determined by father's status, then Table 6.1 shows that the overwhelming majority of interviewees were from families of social classes C2, D and E, though the data is

incomplete.

**Table 6.1: Employment Status of Interviewees' fathers (where known)**

<b>Type of job</b>	<b>Father</b>	<b>Mother</b>
Army	2	
Shop Assistant		2
Factory Worker	4	2
Bank Clerk	1	
Other (Restaurant owner, milkman)	2	
<b>Total</b>	<b>8</b>	<b>4</b>

This limited data accords with Rutter and Madge's findings that 'mild mental retardation mainly occurs in families in which the father has an unskilled or semi skilled manual job' (1976:110), and is probably associated with class and cultural biases in assessment for services (Bryan, Dadzie and Scafe 1985), a factor discussed in Chapter 5. A further possible determinant of social class is the individual's own employment history, and Table 9.1 (in Chapter 9) shows the extent and nature of labour market participation by the interviewees.

Again, and unsurprisingly, the jobs are unskilled manual. Overall, the data suggests that most people were from families where the father was an unskilled manual worker; and even those who were not were downwardly mobile in class terms.

It is possible that there was a class bias in the sample, given that no efforts were made to control for this possibility. However, there is no evidence for this.

Research, such as that undertaken by O'Brien (1994), suggests that there is a correlation between living circumstances and autonomy. This will presumably

impact on peoples' experiences of care. In order to demonstrate similarities and differences relating to living circumstances I divide the group into four according to living circumstances:

Five people who live independently of parents and resident service provider

Four mothers

Four people who live with a parent

Nine people who live in residential care

This has the disadvantage of obscuring an age cohort effect in the life course, but that is addressed in relation to the four interviewees who feature in detail in Chapter 7, where cohort differences are in evidence.

The groupings were based on the situation at the time of interview. People moved from one category to another over time. Several people living independently had lived in hospitals or residential care, for example, but this is obscured by these groupings. However, there was sufficient similarity based on current living circumstances to make this approach useful and informative.

For each group I

- describe the circumstances of their daily lives - housing, day time occupation and leisure pursuits
- summarise what they say about themselves and their current relationships with family, friends and staff. In doing this I also discuss independence, dependence and interdependence as indicated by the Network Diagrams constructed as part of the data analysis (see Chapter 4). This gives a useful pointer to how far people see themselves as receivers or givers of care.
- examine factors which structure dependence, particularly prolonged residence within the family and financial circumstances

## **People living independently**

This group consisted of four women and one man. They were Beryl (60), Deirdre (55), Denise (49), Malcolm (44), Jill (43).

### **Daily Life**

#### *Housing and Living Circumstances*

Beryl, Jill, Deirdre and Malcolm lived in council flats on the North Luton estate where the ATC and hostel were located, a legacy of the practice of housing people within easy reach of services. It is an impoverished area with a lot of vandalism and few facilities, typical of much public housing on the edge of an urban area. Denise had moved recently from a hostel in Dunstable, and lived in a house attached to a newly established staffed group home in an area of mainly owner occupied houses, less conveniently situated for the ATC.

#### *Daytime activity*

None of this group had paid employment. Beryl, Jill and Deirdre went to the Centre (as they called it), and Jill also helped at a nearby play group once a week. Malcolm had recently opted out of the ATC, and attended the *Church Street* Adult Education Centre twice weekly, once for the *Speaking Up* (self advocacy) group, and once for an activity afternoon for people with learning difficulties. Denise was part of *Project Redpact* which sought to provide alternative 'day care' for the residents of group homes, most of whom had recently left hospital (Walmsley 1992 ).

#### *Leisure*

The principal leisure activity mentioned (by Jill, Beryl and Malcolm) was the 'Club', run by MENCAP and established originally for young people. They attended regularly on Wednesday evenings and sometimes on Saturday afternoons, and had done so for many years, and went on the outings organised for parents and their offspring. The Club is one of many such in the UK set up as youth clubs,

whose members were reluctant to move on, as there were few other leisure outlets. Their membership now spans a wide age range (Mencap 1994). Denise did not know about the Club, and seemed more interested in 'dates' with her boyfriend, and outings with the young woman who shares her home. Deirdre preferred to spend her leisure time with her house mate, Kay. She said they went to markets together. When I asked about going out at night she said 'not of an evening, we stop in. You never know someone might come up and mug you'. In this respect she was perhaps more typical of non disabled middle aged women than Beryl, Jill and Denise.

### **Social Relationships**

#### *Independence, Dependence and Interdependence*

In view of the fact that they had achieved 'independent living', a valued goal for adults with learning difficulties (Flynn 1989, Walmsley 1991a), it is not surprising that they stressed their ability to look after themselves. Malcolm said 'I know where to go if I got any problems, you see what I mean.' Beryl explained 'I been brought up with a mind of me own. When me dad were alive he let me handle my allowance.' and Deirdre asserted 'I'm independent now, me and my friend'. An important factor in this sense of self reliance was the ability to travel on public transport. Deirdre said 'We use the buses every day now to come up to the Centre... we used to use the Centre minibuses but they said sorry would you mind coming by shuttle bus so that's what we do'. Of the five only Denise did not travel independently, and this seemed in part to do with her recent move.

#### *Family Relationships*

None of the people in this group relied heavily on family care. I argued in Chapter 5 that people are not given the opportunity to have a home of their own until there is no family available to provide a home. This is borne out by the experiences of this group. Four lived with parents until the last surviving parent died. No one was

younger than 35 when this happened. Jill's history was different, though not unusual. She went into hospital after the death of her mother in around 1974, was discharged and went through a series of moves until she got her flat in Luton. In the interview, at which Beryl was present, Beryl hinted that Jill's father had found her behaviour difficult, hence her admission into hospital.

Most people welcomed the involvement of family. Deirdre said her aunt looked after her 'pension', provided meals and a Christmas welcome for both Deirdre and Kay. Denise's sister intervened on her behalf, for example when Denise was unhappy with her 'home care'. Jane's large family lived nearby, and contact was frequent but not daily. She said they helped her make large purchases and look after her flat, whilst she gave help by baby sitting for nieces and nephews and dropping in on her father. Beryl had contact with family members only on a Christmas card level. Malcolm's family lived at a distance but he hoped one day to move to live near them:

*I have got help up in Nottinghamshire. I got a note out with me brother to look out for a place for me. I got two out, one with my brother and one with my sister.*

### *Friends*

All this group indicated that friends were important. Close friendships were exclusively with other people with learning difficulties. All had at least one close relationship with a same sex friend who provided companionship and, in the case of the four women, day to day practical support. For the women the friendships appeared to be the single most important relationship described. There was a marked degree of interdependence. Two women, Deirdre and Denise, shared their home with a friend. Denise described how she shared the household tasks:

*I do the cooking, Kay can't manage that with the disability what she*

*got, handicapped hand, but um I do the cooking. We share it, do the cooking, washing up, everything .. we don't row.*

Beryl and Jane were neighbours, and visited one another at least daily. Beryl usually cooked Jane's evening meal. All four women had taken holidays with these special friends.

Malcolm, the one man in this group, also singled out a friend as important, but as he lived a bus ride away the contact was less intense. They met once or twice a week, and went to bingo together. Malcolm emphasised the reciprocity of the relationship:

*Jan: You've got a friend you help.*

*Malcolm: Yeah, and he helps me. He got his ideas from me, helping out with the wheelchairs.*

He explained that he was helping his friend's brother who had been moved into a hostel without the consent of his family: 'Andrew's run into a bit of trouble with his brother. And his brother has been over to me to help out.'

### *Staff*

These people played down any reliance on staff, though other than Malcolm, all had daily contact with staff. Beryl described staff as 'keeping an eye on her'. She alone had no direct help in the home. The rest had paid helpers in the home. Deirdre said: 'the family aide comes on Wednesdays, she gives me the money so I don't buy too much.' Denise also had ready access to the staff in the group home next door.

However, the low intensity of contact with staff may not always have been a choice. Both Jane and Deirdre implied that they would welcome more contact with their social workers than was forthcoming. Deirdre remarked: 'I haven't seen him since about August or July now.. I'd like a little chat with him sometimes, you

know.’ Denise felt let down by the *Project Redpact* staff who had promised her a job as escort on their minibus, but hadn’t acted on the promise.

#### *Other contacts*

Several people said they gave help and support to people other than their immediate family and friends. Malcolm and Jane were volunteers. Malcolm had created his own role in the community, and had a well articulated philosophy:

*I’ve been doing it down here, helping people in their wheelchairs and people walking with frames ..Say a well person wants to go to the shops and a person with a frame wants to go to the shops, that’s how we can help one another.*

Malcolm also spoke at self advocacy meetings around the county. This made him unusual in having a public role, outside the immediate confines of his day to day life, and gave him confidence to believe he had something to offer to his friend’s family in their dispute over where Andrew’s brother should live.

Denise looked after residents in the group home next door, and went to an old peoples’ home nearby, though her role there was unclear. She was not ‘old’, but it was not clear from her account that she was a helper. Beryl was on the ATC user committee and visited neighbours from her old home. In their roles as service users Beryl and Deirdre said they gave help to others. For example, Beryl described helping another woman at the Centre:

*Well we got another handicapped girl, well she would have been normal, she in a wheelchair, she can’t walk very well so I push her about when she at the Centre.*

#### *Summary*

Although these people were then living independently, their biographies show how their lives were influenced by prevailing assumptions about the optimum care for



people with learning difficulties, that is living within the family until it could no longer provide. This family care was buttressed by services like the Adult Training Centre, or, in the case of Jane and Malcolm, replaced by hospitals when the family unit broke up. Opportunities for living in their own households came late in life, and were influenced both by the death of parents and changes in philosophy. This is consonant with the findings described in Chapter 5.

No one was in paid employment, and all relied on state benefits. Money was not discussed a great deal, but of them all only Malcolm appeared to have full control of his finances. Beryl, robustly independent in many ways, relied on staff for writing cheques. The structural factors which sustained their financial dependence appeared to be so much taken for granted that no one questioned it, or expected it to be otherwise.

Overall, the way services had been organised in Luton had dictated where people lived, and to a large extent where they spent their time. This also provided a fairly robust framework for their relationships. Beryl, Jill, Malcolm and Deirdre had both benefited from and been confined by the relatively unchanging services. They knew their way around, their environments were familiar, the people were familiar. Though Malcolm had opted out of the Centre, he still attended the Club. Their networks were almost exclusively with other people with learning difficulties, staff and, sometimes, family. Denise provided a contrast. She had moved recently, and had not joined the ATC, the result of a shift in policy which was attempting to diversify day activities through initiatives like *Project Redpact* (Walmsley 1992). She did not know her way around, nor did she know the people who comprised the overlapping networks of the other four. She lived at a distance from that community, and seemed less secure and certain of her place.

The way people described their relationships suggests they saw themselves as more than just dependants. They emphasised their ability to look after themselves, to help

others, and interdependence with friends more than needs for care and support. Whilst for the women this was mostly expressed in terms of shared domestic tasks, or lending a hand to other service users, there was a more public dimension to Malcolm's activities.

### **The mothers**

All this group were in their thirties. Despite numerous attempts I could locate no mothers over the age of 40, and no fathers at all. I was told of women who had lost their children, but it was not possible to contact them. One was living with her husband, but did not answer my letter. For others I was told it would be too distressing to bring up the past.

The four mothers were Sheila (38), Alanna (in her thirties), Alison (32) and Stella (30).

None of the mothers used mainstream learning disability services, and all were contacted through Bedfordshire's Special Adult Learning Programme (SALP). Three of the four had acquired the 'learning difficulty' label through special school. The fourth, Stella (the only Black interviewee), had attended mainstream school and blamed her backwardness on her treatment as a mental patient: 'after taking these drugs I get very backward'.

### **Daily Life**

#### *Housing and Living Circumstances*

The four mothers were Sheila, who lived with her husband and five children in a council house on a pleasant estate; Alanna who lived with her son in a house near her mother; Stella who lived alone in a flatlet on the North Luton estate where Jane, Malcolm, Beryl and Denise lived; and Alison who was temporarily lodging with her ex husband when we met. These are the only interviewees who established their own households in early adulthood, and this was associated with marriage (in two

cases) and parenthood (in all four cases).

### *Daytime Occupation*

None of this group was employed outside the home, nor did they attend 'day care' of any kind. For Sheila and Alanna being a mother was a virtually full time occupation, though all the children attend school. Stella went to college classes once a week, visited her fostered daughter fortnightly, and went to the Church Street Centre for literacy classes. Alison also went to literacy classes for adults with learning difficulties, and mentioned nothing else.

### *Leisure*

No one mentioned any regular leisure activity outside the home, other than the classes they attended. Alison wrote poetry and stories. Alanna did keep fit to home videos, and kept her house and garden in order. Sheila did dress making for her children. Stella mentioned only her fortnightly visits to her daughter.

### **Social Relationships**

#### *Independence, Dependence and Interdependence*

These women emphasised their competence. Sheila mentioned that she might have had another life:

*There was a girl my age, she had the same opportunities as me (to go to boarding school) but her parents wouldn't let her go .. she can't do none of it, just stayed with her parents, her mum anyway.*

Sheila was bringing up five children:

*Mum always said up to the time she was here sort of thing how well we were doing. I've heard that other people with one child has to have help. We just get along day by day.*

Alison was adamant that it was her decision to have her six children adopted:

*I asked my social worker to put my two eldest children into care and I did not want my third child after I'd had him, but it does not mean I do not love them because I do. They are all very special.. they need a safe place to grow up. They have a right to a childhood. I want them to have what I never had.*

Stella resisted the diagnosis of schizophrenia and the loss of her child:

*They say there was something wrong with me, there was nothing wrong with me, I didn't have anywhere to live and my mum wouldn't take me in.. The reason I went in there (psychiatric hospital) was cos I had a breakdown about not having her with me, see, I got very depressed about it.*

Alanna's self confidence was less robust, but she was proud of her achievements in bringing up her son. Her story is explored in more detail in Chapter Seven.

#### *Family Relationships*

Whilst for the other interviewees family means family of origin, these four women had a more complex set of family relationships which included their own families. This complicated the picture of relationships.

All four regarded being a parent as a very significant identity, and the interviews revolved around their children, even in the two cases where children lived elsewhere. For three of the four mothers families were their principal social contacts.

Sheila was the only interviewee who lived in a conventional nuclear family, with her husband and five children, and had regular contact with her husband's brother and his wife who were, she said, her main source of support outside the home. Sheila stressed the importance of her parents' encouragement for her success in establishing her own household, but made it clear that practical help from her parents was limited:

*She (mum) helped us when we were stuck or anything with forms she helped*

*me. No, she would never look after me kids, she always looked after me sister more than me.*

She said her relationship with her husband was good, though commented on the fact that she has to carry on regardless of how she feels:

*He gets a bit tired from work and I have to sit through it, just carry on, if I am feeling rough I still got to get up, get the kids to school.*

Her children ranged in age from 18 to 6. All but one was in special education, but, she says, 'they are all brighter than what me and me husband are'.

Alanna and Stella's lives were also primarily dominated by family. Alanna's son lived with her, and she had regular contact with her mother, and less regular contact with her father and brothers. She resented her mother's efforts to maintain control over her son's upbringing. Stella lived alone. Her daughter lived with another family. She saw her only fortnightly. She recalled how she had looked after her daughter:

*My first child and I look after her, I was glad to have her and everything. I feel let down really cos they could have exchanged the flat. She wants to come back home to me. Sad really. The only child I've got you know. I'd like to have her back, look after her hair.*

Stella's mother looked after her money, decorated her flat, and cooked meals for her. Stella had mixed feelings about the dependence this indicated which are examined in more detail in Chapter 8.

Alison's six children were either adopted or in the process of being so. She had worked with social workers to secure their futures. They were still important to her, but not on a day to day basis. She had no contact with her mother. Her father was dead. Her only positive family contact was with her first husband whom she described as a friend. She was living with her second husband and his new partner.

## *Friends*

Friends did not feature in these peoples' accounts. As Sheila explained:

*I don't have many friends, I don't go up the school, the children get picked up by taxi so I don't really meet anyone at school no more .. me husband don't like it anyway if I talk.*

And Alanna described her situation: 'Since I haven't got any friends when she (*mum*) is well we go out to places like town.'

Alison mentioned only her first ex husband as a friend, and Stella made no reference at all to friends.

## *Staff*

As they were without specialist learning disability services, the contacts the mothers had with staff and services were more diverse and less frequent than for most other interviewees. Indeed, Sheila had no regular contacts with social services. Alanna and Alison both had social workers. They described them as supportive, and relied on them as confidantes and for practical support. Alison explained:

*I always thought I'm old enough to look after meself. If I can't I take it out on my doctor, my counsellor or my social worker.*

Alanna saw her social worker as a friend, and this is explored in Chapter 7.

Stella's contacts with service providers were more punitive. She said she had no social worker, and resented the psychiatric service who administered her drugs:

*Yeah for no reason they think I'm stupid, they think I'm really stupid you know, push me around a lot.*

A recurrent theme in the interviews was that no one had explained to her why her daughter had been taken away.

Other than service providers the only other regular contact mentioned was the

Church Street Adult Education classes through which these women were contacted for the research. Alanna, Stella and Alison went regularly to classes where they met other students, though none mentioned any friends there. Stella dissociated herself from the others in the class:

*I do cookery up there .. with some handicapped people you know, I talk to them, I try to help them standing beside me doing the cooking.*

### *Summary*

The lives of these four mothers were very different from those of the five childless people who lived independently. This seemed to be linked to their parenthood. It took them out of learning disability services, and away from the regular companionship so characteristic of the lives of the other five. They all established their own households in their twenties. They seemed quite isolated, and thrown onto the resources offered by their families and in two cases paid professionals. In this respect they appear to have much in common with other working class women (Oakley and Rajan 1993). Their giving of care was primarily to their children. Reciprocal relationships appeared to be non-existent (except Sheila and her husband), and support was from families and/or paid workers.

This group shared with other women structured dependence within the family or the benefit system (Showstack Sassoon 1987). Their learning difficulties appear to be less significant than this gender based dependence. Of all the groups, they had most financial autonomy, albeit with small incomes. Stella was the exception. Her mother controlled her income. However, none had an income from paid work, and Stella speculated that her daughter had been taken from her because she was unemployed.

Overall, then, the mothers' lives seem less influenced by their label 'learning difficulty' than by factors associated with gender and social class. This is not

dissimilar to the findings of Booth and Booth (1994) who argue that parents with learning difficulties have problems with parenting more because they are socially and economically disadvantaged, than because of their learning difficulties as such.

### **People who live with a parent**

The four people living with parents were Eileen, Barry, Lynne and Jacqueline, all in their forties. According to Simons (1992) over 60 per cent of adults with learning difficulties live with their families of origin; and it is these people who are the subjects of those many studies which examine the burdens of caring to parents (see Chapter 2 for references).

### **Daily Life**

#### *Housing and Living Circumstances*

Eileen lived with her seventy year old father in a privately rented house which until recently lacked even basic amenities - a bath, hot water, telephone. I was told by an ATC worker that these were installed after intervention by a social worker when both Eileen and her father became ill. Barry lived with his mother and brother in a large village north of Luton. Both Jacqueline and Lynne lived in tower blocks on the North Luton Council estate. Lynne lived with her father (in his sixties and quite severely disabled) and Jacqueline with her eighty year old mother. All of these households were long established, the most recent move being Jacqueline's family who relocated to be near the Centre after Jacqueline's father died 25 years prior to the interview date.

#### *Daytime occupation*

All four people began to attend Bramingham Centre in the year it opened, 1966, though Lynne left in 1984 to begin work at a pharmaceuticals factory where she was still employed. Barry worked part time at a Garden Centre for the maximum wage he could earn before loss of benefit, twelve pounds a week (in 1992), and also



went to the Centre. Jacqueline and Eileen were both full time at the Centre. Jacqueline's mother pointed out that there was little to differentiate the Centre from leisure time:

*You see when they used to have their little jobs she always used to come home, she'd be quite willing to crayon and copy writing, well now looking at books all day she just doesn't want to sit and do all that again.*

However, policy on contract work in ATCs appeared to be inconsistent. Whenever I visited Eileen at the Centre she was assembling small boxes for oil paints.

### *Leisure*

These people all attended the MENCAP club regularly, and went on the outings. Eileen spent some weekends and evenings with Beryl, and identified her holiday with Jane and Beryl (both interviewees) in 1989 as the best time of her life. Other than the Club, Jacqueline only went out with her mother, shopping and visiting relatives. Lynne had a number of leisure activities including the Salvation Army, gardening classes at the hostel, and met her boyfriend Eddie every day after work, and occasionally at weekends. They went to the Club together. Barry had a girlfriend, Isobel (also an interviewee), and they went out together on Saturdays, and also had holidayed together on at least one occasion.

### **Social relationships**

#### *Independence, Dependence and Interdependence*

An indicator of independence is ability to travel independently. Barry, Eileen and Lynne moved around independently on public transport - though Eileen, like Denise, was unwilling to go out alone after dark.

Jacqueline was different. Her eighty year old mother was present at the interviews, and answered for her. This was the only time I got a parent's view on the question of care and dependency, and the picture contrasted sharply with the results of all the

other interviews. Mrs. M clearly saw Jacqueline as dependent on her, acknowledging only that Jacqueline did minor household tasks - making tea, dusting, laying the table. She described how she met Jacqueline on the ground floor of the flats when she came home:

*I go down to meet her now, she doesn't mind coming up on her own, but it (lift) breaks down quite often and she wouldn't know what to do you see.*

It is a moot point whether Jacqueline would have described things differently had I been able to speak to her away from her mother. Certainly there appeared to be a difference between Eileen, Lynne and Barry who moved around freely whilst Jacqueline was always supervised. It was hard to judge how Jacqueline regarded herself. In the presence of her mother it seems she accepted her mother's view of her as someone needing loving care and constant looking after.

### *Family*

All this group had always lived with their families. In this sense they had lived stereotypical lives, forever the children at home, watching siblings leave and marry while they remain. It was not unlike the lives of Beryl, Denise, and Deirdre. Once their parents were dead they had moved on to live in their own households. This was a stage the people in this group had not yet reached. (Since I completed the fieldwork Beryl told me that Lynne's father had died, and she now lived in the flat alone, and Jacqueline's mother was also dead. Jacqueline had moved into a privately run group home where Anna, another of the interviewees, lived.)

It would be a mistake to see these people as 'dependants'. Three of them described themselves as looking after their parents. (see Chapters 7 and 8). They also expressed with varying degrees of certainty the wish to escape family life. Barry said: 'not being nasty but when me mum goes I'd like to live with Isobel'. Lynne wanted to live on her own 'before I get too old', and though Eileen initially gave

the impression that her sister's offer of a home was welcome - 'that would be nice cos I could help her then, couldn't I?' - under pressure from Beryl, also present at the interview, she conceded 'a group home, that might be nice'.

### *Friends*

All this group described friendships. Eileen's friendship with Beryl was important to her. She stayed at Beryl's flat for weekends. They holidayed together and met at the ATC. The relationship was reciprocal, at least on the surface, though its nuances suggest that it was not entirely balanced (see Chapter 8). Barry had a girlfriend, Isobel (another interviewee), and Lynne had a boyfriend, Eddie. Both these relationships had elements of reciprocity in terms of companionship and practical help, for example Eddie helped Lynne with the shopping. Lynne was the only person to have significant relationships with non disabled people, talking of 'my best friend at work'. Of the four, Jacqueline's friendships seemed least significant. Again this may be a consequence of the interview situation. The friend she mentioned, Eileen, made no mention of her. Her mother's friends at MENCAP were described by Mrs. M as being Jacqueline's friends also.

Day time occupation was a crucial determinant of the social relationships of these four, as it provided the main alternative to family life. Eileen and Jacqueline's friends were at the Centre. Eileen valued her intermittent care giving to others at the ATC. She told me she was occasionally allowed to assist in Special Care, the unit for people with more severe disabilities. Jacqueline mentioned no such opportunities. Both know the people at the ATC well, each having been there for 25 years.

Work gave Barry and Lynne access to wider networks. This is a finding in line with much research on the importance of paid employment as a route to social integration for adults with learning difficulties (Eaton 1994, Walsh and Lynch 1994). Work appeared to act as a spur to contact with the community, for example

Lynne visited the Building Society to collect her wages. Both Lynne and Barry took part in activities in a wider sphere. Barry was a member of the User Forum, which brought him into contact with other members, parents and service providers, on a relatively equal footing. Lynne went to the Salvation Army, where she sometimes helped to sell the newspapers and run coffee mornings.

Despite their status as employees Barry and Lynne spent the majority of their leisure time with other people with learning difficulties; their friends were people with learning difficulties, they went to the MENCAP Club, as did Jacqueline and Eileen. Lynne occasionally popped into the local hostel to have a chat, and we met there for our interviews.

### *Staff*

Staff were present on a daily basis for all but Lynne whose situation was more complex as the majority of services were provided for her father, not her, and this gave rise to particular stresses, examined in Chapter 7. No one indicated substantial dependence on staff. Instead they were talked about as friends by Eileen who said of one ATC instructor 'he's a laugh', and as colleagues by Barry, especially those he knew through the User Forum.

### *Summary*

The assumption that families will provide a home as long as they can has structured the lives of this group. None had the opportunity to leave home in early adulthood which is the cultural norm for young people (Wallace 1987). The way services developed in Luton had been a major influence. Because of their age, in their mid teens when Bramingham opened in 1966, they were the first generation to benefit from the provision of community services for children and adults. Mrs. M said the proximity of the Centre influenced her to move to North Luton after her husband died.

This dependence was also financial. This was in part a result of the 'benefit trap', which discourages the take up of paid employment for fear of loss of benefit (Davis, Murray and Flynn 1993), but families also exerted control. Lynne gave most of her wages to her father as 'board money'. Barry said he'd been discouraged from increasing his work hours by his brother because he'd lose benefit, and become liable for poll tax. Eileen said of money 'No, me dad does that. I'd love to, one day, if something happens to him.'

The lives of this group demonstrate the complexities of care, dependence and interdependence. Three people had become supporters of parents as they aged and became infirm, yet remained bound by structural features which sustained an apparent, and in financial terms, real dependence within the family. The ATC may have helped families to cope without a need for hospital or hostel placements. It also supplied friends and acquaintances, and a certain stability and predictability which contributed to the static nature of their lives.

### **People living in residential care**

There were nine people in this group, three women and six men. They range in age from 70 to 30. Bert (55), David (42), Janette (36) and Mike (30) lived in hospital. Gordon (70), Arthur (61), Anna (53), Isobel (46), and Gary (38) lived in staffed accommodation.

### **Daily Life**

#### *Living Circumstances*

The hospital residents lived on a mixed sex ward in Bromham Hospital. It was a two storey villa dating from the 1930s. The lower storey comprised day and dining rooms, the upper storey had sleeping accommodation. Both Bert and Mike commented on the problems of hospital life. Mike said:

*You don't know what the patients are like in here .. keeping your stuff, one*

*hell of a problem I tell you.*

None had their own room.

The other five were former residents of Bromham or Fairfield Hospitals. Gordon and Arthur lived in a staffed group home together, and Isobel lived in a similar house nearby, having moved there from Waulud's hostel during the period of the fieldwork for this research. Anna lived in a privately owned and run home with four others, and Gary lived in a privately owned hostel with 13 other residents in a town in Bedfordshire. All had their own bedrooms, but no private space other than that.

#### *Day time occupation*

Daytime occupation was a mixture of voluntary work and Day Centre activities. Three of the men did voluntary or so-called therapeutic work for which they could be paid up to a maximum of, at this time, £12 a week without loss of benefit. Bert helped the hospital porter five days a week, cleaning out vans and delivering food trolleys. Gary also worked in the hospital helping with laundry for therapeutic wages of £12 a week. Arthur had a volunteering job at a day centre for homeless Irish men where he washed up and did other odd jobs.

Mike and Janette were bussed from the hospital to the Biggleswade Training Centre on four days. Isobel and Anna both went to Bramingham Centre five days a week.

Gordon, who was 70, spent most of his time in the group home. David did nothing much, as far as his account went.

#### *Leisure*

People's leisure activity seemed to depend on their ability to travel alone. Gary had the most extensive leisure activities. He lived in the centre of town, and attended numerous clubs and classes for people with learning difficulties, as well as travelling to jumble sales with his mother at weekends. Isobel met Barry at the

Centre, and at weekends, and had been on holiday with him.

None of the others travelled independently, and they all relied on staff for leisure outside their homes. Gordon exchanged fortnightly visits with Carl, an old friend from hospital days, an enterprise which staff facilitated. Arthur had a volunteer befriender, though indicated that he was unreliable:

*He buys a pot of tea out of his own money, very nice of him isn't it .. he ain't come since Saturday 22nd August, never come weekend before last, never come last Saturday.*

Anna eschewed the activities laid on for her co-residents - concerts and outings to local sights.

The hospital staff acknowledged that the hospital had little leisure activity to offer, and this is reflected in what residents said. Janette went to her family at weekends. Mike told me he and Bert did weight lifting to keep fit for fights with other patients. Bert cycled around the local villages. David mentioned having a game of dominoes, but said when I asked about his day, 'well there's not a lot I can do really'.

## **Social Relationships**

### *Independence, Dependence and Interdependence*

For this group dependence on staff was almost inevitable. The opportunity to look after themselves was quite limited. All were catered for domestically, and only two people travelled independently. Isobel, Gary and Anna kept their own rooms clean and tidy. The four hospital residents, Gordon and Arthur were fully serviced by staff. Gordon and Arthur had their smoking regulated. I was reprimanded by the Group Home Manager for bringing cigarettes as a gift to Gordon, and Arthur was given five cigarettes a day to take to work with him.

## *Family*

Although no one depended directly on family care, families continued to have a significant impact on peoples' levels of dependence on services. All four hospital residents had contact with family, ranging from Janette's regular weekends at home to David's longings for his family to take him home occasionally:

*Other people go home and I don't, you see. And I'd like to but I don't know who to ask.*

Families represented a bridge from the hospital to home. Bert hoped to work and live with his brother when he left, and Janette's weekends at home resulted in her being known to several of the respondents who live in Luton. There were, however, no opportunities for family relationships to be either symmetrical or reciprocal. Families appeared to the respondents to have the choice whether to maintain regular contact or not; as Mike put it:

*But staff's gotta ring up see if I can go home, but my mum will have the last say, me mum will have the last say if I can go home.*

Of the five people living outside hospital, only Isobel and Gary had parents living. Families could extend peoples' social contacts significantly. Gary visited his mother most weekends. His father visited him regularly and supplemented his 'pocket money'. Gary's large family provided him with numerous social gatherings, as well as continued contact with old friends in Luton, both people with learning difficulties and their parents in 'the Society' (MENCAP). It was hard to imagine Gary sustaining these contacts without family to transport him.

The others had little benefit from family relationships. Isobel's parents were alive but lived at a distance. She mentioned several times their liking for her boyfriend, Barry. Anna seemed to have lost contact with her family early in life, and Arthur and Gordon's parents were dead. Gordon had no known family. Arthur spoke of his



stepmother and brother, but rarely saw them. He remembered their birthdays.

### *Friends*

From the interviews it was hard to deduce whether the four hospital residents had significant friendships. Other patients were the major source of friendships for very practical reasons. Mike claimed Bert was his friend, though Bert denied this. Janette mentioned two women friends she saw, though would say little about them. David, after much thought, said he had one friend with whom he plays dominoes. Bert and Mike both emphasised friendships with staff and distanced themselves from other patients. Bert also had a long distance relationship with a patient in a hospital in Staffordshire. He got the nurses to write to her, and spent time wondering what gifts to send (see Chapter 7).

It was more common for the residents of group homes and hostels to describe friendships. Two had close opposite sex friendships, quite rare amongst the interviewee group. Isobel had a boyfriend, Barry (another interviewee), and Gary had a girlfriend, Sally, who lived in the next door room in the hostel. These relationships provided opportunities to give and take affection, companionship, and practical support. Isobel and Barry made it clear that they were lovers. However, neither couple had the autonomy to develop the relationships as they might wish. I asked Isobel if she'd like to live with Barry, and she answered: 'I'd like to, yeah, not allowed to yet.' Gary said they were engaged but could not marry, 'with all the fits we get they don't think we could manage'.

Anna's and Gordon's friends both lived at some distance, and there were difficulties in meeting, but for both the presence of physical disability symbolised the need for help from an able bodied friend. Gordon described it thus, pointing to a photograph:

*Fairfield (hospital), Ward F3, Carl in a wheelchair, took him to the toilet at*

*Fairfield, walk him back in the dayroom, television room, see he's in a wheelchair, see Carl here.*

Anna's friend was Hazel: 'I got a friend, her name is Hazel, at Lincoln House, she in a wheelchair'.

Other friends came from within the home. Arthur and Gordon shared their staffed group home with two other men. Three knew one another from hospital days. They took an interest in one another's activities, ate together, chatted together though did not socialise much outside the home. Isobel had two friends in her house, Lynne and Martin. They moved out of the hostel together, and shared household tasks, as well as meeting at the ATC. Anna shared little with other residents. They went out to the Club, concerts etc. She stayed at home, with a member of staff.

Gary's friendship network was more extensive. Because of his frequent visits home he maintained contact with MENCAP people in Luton he knew in his youth, and peppered his conversation with references to them: 'Do you know Mr. and Mrs. Salt, they belong to the Society', 'Lindsay Smith, she's a little mongol girl'. Gary had not lived in Luton for about 15 years, so this indicated a very durable network.

### *Staff*

Daily and frequent contact with staff was part of hospital life. The three male hospital residents described some elements of reciprocity in their relationships with staff. David said he made the staff cups of tea sometimes. Bert told me about courting nurses, and both he and Mike claimed to act as trouble shooters, protecting the nurses from the violence of other patients; Mike described what he did:

*Helping the staff keep order keeping the lads and lasses under control, pulling the glasses off your face.*

However, a more one sided relationship with staff was revealed to me when the tea bell rang. All obeyed, and lined up quietly for their drugs.

Although this group were apparently dependent on the care given by others, none emphasised this in their interviews. A polite silence was sustained on that dimension of their lives. The reasons for this can only be speculative. I discuss in Chapters 8 and 9 the difficulties men may have in acknowledging that they are subject to care from women who are neither relatives nor sexual partners. On the other hand, the fact that I did the interviews in the hospital may have meant that the interviewees assumed I could see the nature of their relationships with hospital staff without being told.

There was greater variety in the non hospital group. Gordon spent his days in the Group Home. The staff there cooked for him, dressed and bathed and shaved him, cleaned up for him, and arranged for him to meet Carl. I sensed a quasi maternal relationship when, whilst I was visiting his group home, one female member of staff presented him with a pullover she had knitted for him. Anna relied on Mary and Ron, the resident owners of her privately run home:

*They are there all the time. If I don't want to go out somebody there to look after me, see.*

She kept her room tidy, but all other household tasks were done for her. Mary and Ron arranged her holidays, took photos of her and generally provided the framework of her life. Unlike Gordon's paid carers they did not facilitate contact between Anna and her friend Hazel, because of the physical barriers - transport, toileting. Anna had no opportunity to reciprocate their care, except by being compliant and untroublesome.

The other three also relied on the paid staff in their homes to a greater or lesser degree. These were universally one way relationships. Gary, for example, said:

*I get on with 'em (staff). As I say I get me ups and downs .. and I was a bit irritable, but they soon accept my apology. I can't bath myself. If I have a*

*bath there's always someone sitting outside till I come out.*

No one presented the staff as anything other than paid helpers.

### *Summary*

The impact of changing services on these peoples' lives was evident. They had moved through family life into hospitals, hostels and group homes as fashions and beliefs about the optimum environment for people with learning difficulties fluctuated. Anna, for example, had moved five times since leaving hospital. Within residential accommodation dependence on others was also structured. Mary told me that Health and Safety regulations meant Anna could not use the kitchen, and the Homes Registration Officer's regulations meant she could not be left alone in the house.

The lives of the hospital residents appeared to be impoverished in many respects, with limited opportunities for social contact outside the hospital. Those who did have a life outside relied on family for it. Despite this stereotypical state of dependency, in almost all respects, it was a topic no one chose to articulate. This was less true of the other five people whose level of independence varied from Gary's quite active life to Gordon's enclosed existence within the home.

Financial dependence was almost total. Gary referred to his dad giving him 'pocket money', and to his 'pension'. He did have some cash to spend on Sally and himself when he was out shopping, but his earning power was limited by the nature of therapeutic earnings. Neither Gordon or Arthur even had the money to buy extra cigarettes. Anna was saving her £1 50p a week wages from the ATC to buy a birthday gift for a young neighbour.

Within this group other than through friendship, or, rarely, through work, people were very much the receivers of care, particularly from paid workers. One feature which differentiated this group from those described above was this reliance on

professional support. In the case of the hospital residents, and Anna and Gordon, this represented quite a fragile network. The absence of family and close local ties made them vulnerable to change. By contrast, there was every indication that if Gary's hostel closed he would weather the change. His network had many durable elements thanks to his large and attentive family.

A gender dimension emerges in this group overall. Though the ratio of men to women in the sample was 1 to 2 the majority of men were in residential care. This may indicate a bias in the sample, or, possibly, an assumption that men are less likely to be able to care for themselves. It also introduces a query about how men handle being dependent on, and perhaps controlled by, mainly female care staff. This will be examined in more detail in subsequent chapters.

### **Chapter Summary**

This chapter set out to describe people's current circumstances and relationships, and to explore two of the themes identified in Chapter 5, the role of families and the impact of changes in services on individual lives. It also begins to frame some themes around care and dependency which are picked up in subsequent chapters. In this concluding Section of Chapter 6 I outline these themes, and discuss how the findings in this research compare with existing research into the lives of adults with learning difficulties.

It was true of all the interviewees that they had a fairly limited set of social contacts, mostly falling into the categories of family, friends and staff. This is consistent with research into the social networks of adults with learning difficulties (see Atkinson and Williams P 1990 for an overview of the literature). For users of services there was also contact with other users, in some cases offering opportunities for care-giving.

Sexual partnerships were the exception, not the rule. Only one interviewee, Sheila,

lived with a partner. Of the six others who mentioned boyfriends/ girlfriends, only two acknowledged a sexual relationship, and none had any definite plans for cohabiting. Again, this is a common feature of the lives of adults with learning difficulties, as shown by Jenkins (1989) and Brown (1994).

The role of families emerged as significant well into adulthood for the majority of interviewees, the exceptions being those few - Anna and Alison - whose families either rejected them, or were rejected by them, in early life. Most interviewees tacitly accepted the 'naturalness' of family care, and few questioned their continued reliance on family for certain benefits, ranging from a home for those people still living with parents to visits and trips out for people in hospitals and hostels. Given the prevailing ideology, described in Chapters 2 and 5, that the best environment for adults with learning difficulties is in their family home, the fact that few interviewees questioned this suggests that they, too, were aware of it.

The failure of families to provide care made people vulnerable to fluctuations in policy and practice in residential care which are mirrored in individual biographies, especially obvious in those who left their families early in life. The role of families in relation to hospital residents has not been a specific research focus, but findings from oral history projects - Potts and Fido (1991) and Atkinson (1993) - emphasise how much hospital residents value continued visits from family

Fluctuations in residential services are in marked contrast to the stability of day services which in 1992 had changed little since Bramingham was established in 1966. The ghetto effect created by the establishment of the ATC and hostel in North Luton had limited opportunities and congregated people in an area of deprivation and poverty generally. However, there were some positive aspects. The unchanging pattern of services created continuity. Those people who were members of the ATC and Club were in familiar territory where they knew others in the same community of interest. Even people like Michael and Lynne who had opted to leave

day services chose to go to meet friends at the Club. Physical absence from that community did not always mean exclusion. Gary enjoyed meeting old friends in MENCAP. Jane when she returned to Luton was able to pick up old relationships, and join in familiar activities. In 1992 the congregation of services was beginning to break down - Isobel had moved away recently, alternative day provision was being pioneered by *Project Redpact* and the new group homes were scattered around the town.

The importance of continuity in community services for maintaining existing friendships has been little explored in research terms, and was not an issue I set out to explore. This finding does suggest that the emphasis in normalisation on dispersal of services, and relationships with non disabled people (McConkey and McCormack 1983, Butler, Carr and Sullivan 1988) may need re-adjustment to take account of the incidental benefits of segregated services.

Two additional themes which emerge from this overview are the significance of gender and sexuality, and the way people described themselves and their relationships in terms of independence, dependence and interdependence.

In relation to gender, I noted in passing the importance women assigned to sharing domestic tasks with other women, and the greater likelihood that women were expected to look after their own domestic needs in residential care. In most cases the absence of partners and children meant that obvious opportunities to be carers which occur in the lives of wives and mothers were absent. But women in this group did begin to claim caring responsibilities for others in different spheres, such as in relation to fellow service users. This differentiated them from the male interviewees whose most prominent interests were in caring for girlfriends (Gary and Barry), or in their voluntary work (Michael, Barry and Arthur).

Linked to this is how people represented themselves in the context of dependency. People used certain language about care - *looking after* and *helping* - and they did

not readily describe themselves as dependants. Few people openly acknowledged the need to be cared for. Those who did - Anna and Gary, both residents of private homes - termed it 'looking after'. Many more people, men and women in all four groups, laid claim to interdependent relationships and to being helpers in a variety of contexts - friendships; in relation to other users of services; and as volunteers. Even in the unpromising context of hospital three interviewees described helping activities.

This contrasts with factors which structured continuing financial dependence. Other than Lynne, no one earned a wage above the maximum allowed before loss of benefit, at the time twelve pounds a week. The degree to which this was accepted is indicated by the fact that the only interviewee who spoke of unemployment was Stella.

The chapter has signposted the way forward for further description of the findings. In Chapter 7 I look at all these themes - family, services, gender and identities around care and dependency in relation to four individuals who represent the four groupings here, and who also represent four age cohorts - people in their sixties, fifties, forties and thirties. In Chapter 8 I examine the way people talked about care and dependency within their relationships using the categories family, friends, and staff identified in this chapter.



## **Chapter 7: Representative Lives?**

### **Introduction**

In this chapter I present the lives of four respondents: Beryl, Bert, Lynne and Alanna. Each represents one of the four groups discussed in Chapter 6, and one of four age cohorts, present in the interviewee group, namely people over sixty, in their fifties, forties and thirties. This builds on the discussion in Chapter 6 of the interrelationship between social and personal factors in peoples' lives. The Chapter title, 'Representative Lives?', poses the question of how far it is possible to identify factors influencing the lives of an age cohort of people labelled as having learning difficulties. The use of biographies to illuminate social factors has been pioneered in sociology by Elder (1974) and Bertaux (1981), among others. However, this study does not permit such an exhaustive analysis. As I explained in Chapter 4, lack of data made it impossible to aggregate the data from life maps in a meaningful way. An individual life can only give an indication: 'Every biography will therefore exhibit the common influences of the social structure as well as the idiosyncrasies of individual response and action' (Humphrey 1993:167). There is no one typical career of people with learning difficulties according to age cohort, just as there is no single Jewish women's history (Jewish Women in London 1989:8), and no uniformity in the life course of old people living in an ex mining town (Humphrey 1993), but there may be commonalities.

A further reason for refashioning the interview data into what I have called auto/biographies is that I interviewed individuals, and it is important that they continue to appear as such so that the reader can begin to appreciate idiosyncratic styles and narrative forms.

The apparently straightforward idea of using biography to give real meaning to the idea that we are socially constructed (Evans 1993) has proved in practice to be fraught with tensions, ethical and practical. Oral historians differ in the extent to

which they accept that the individual narrative can represent historical meaning. Passerini writes of 'The impossibility of making direct use of oral memories as immediately revealing facts and events' (1989:194); and Denzin warns 'If we foster the illusion that we understand when we do not or that we have found meaningful coherent lives where none exist, then we engage in a cultural practice that is just as repressive as the most repressive of political regimes' (1989:83). However, writers in a feminist tradition, such as Chanfreult-Duchet, argue that the job of the oral historian is to convert information from narratives into 'information of a sort relevant for the discipline of history and this is achieved by focusing on the vision of history, the social models and the symbolic representations at play in the narrative' (1991:82). This position is the one I adopt in this Chapter.

Questions were raised by the presentation of these accounts as auto/biographies. There was no neat chronological account in any of the interviews. Respondents ranged to and fro across their past and present lives, often unsure themselves of the precise order of events. Conventionally oral historians imposed a chronology on individual life stories regardless of the way respondents have chosen to represent their lives (Bornat 1993). If the aim is to make links between historical events and the landmarks of individual biographies a chronological account is more manageable. But it violates the individuality of personal accounts and imposes a writer's structure on what was often in practice a coherent oral account. Hence the choice of the term 'auto/biography' to indicate that the accounts here are the product of the oral autobiography and the written biography which I construct from the interview data, representing an interplay of personal and interpretive material.

The chapter draws on themes developed in Chapters 5 & 6. Substantial extracts from the relevant parts of the transcript are included as Appendix 4 so that the edited version can be compared with the raw data. Each of the reconstituted auto/biographies is structured as follows:

Interview situation - a description of the circumstances of the interview

Auto/biographies - a chronological account of the lives as presented in the interviews. Other data garnered en route is inserted in parentheses [].

Analysis - an analysis of the life story data using categories developed in Chapters 2, 5 and 6: the role of families; the impact of services; and identities around gender, caring and dependency.

### Choice of respondents

Of the 22 people who contributed to the field data, four were chosen for detailed reconstituted auto/biographies in this chapter. There were 14 respondents who in my judgement had provided enough detailed information to make a reconstituted auto/biography a practical proposition. Having identified these I constructed the following categories to be covered: range of ages; gender; living independently/ living with family / living in hospital / paid worker / parent. I narrowed the choice to six by this means, and the choice of the final four was based on the richness of each account. The following table illustrates how the four cover the categories:

**Table 6.1: Categories covered by the Auto/Biographies**

<b>Name</b>	<b>Age</b>	<b>Gender</b>	<b>Living Circumstances</b>	<b>Employment</b>	<b>Children</b>
Beryl	60+	Female	Own home	Semi retired	None
Bert	50+	Male	Hospital	Sheltered	None
Lynne	40+	Female	Family home	Open	None
Alanna	30+	Female	Own home	Mother	One

Regrettably this excludes those people who were most active in the public arena (Malcolm and Barry), the mothers who had lost custody of their children (Stella and Alison) and residents of group homes. This was the result of limiting my choice to four respondents and prioritising other categories.

## **Beryl**

### *Interview situation*

I was introduced to Beryl by her friend Eileen, another interviewee. Eileen had mentioned Beryl in both her interviews, and as I was looking for other interviewees I asked Eileen to introduce me. I formally interviewed Beryl only once, in company with Eileen, at Beryl's flat. But I met her on many other occasions. She and Eileen accompanied me to the 1992 Women First Conference, in Nottingham, at my invitation, and we met both before and after that event. She joined in one of the interviews I had with Jane and subsequently I was invited to tea at her flat with Eileen and Jane. The frequency of our contact, and the fact that I observed her interactions with several other people, means I felt I got to know her (and Eileen) quite well. She has no obvious disability other than indistinct speech. She was at first politely patient with my attempts to understand or my pretence at grasping what she had said when I hadn't, but by the time of the tea party she was quite impatient with my misunderstandings.

At the time of the interview (1992) she was approaching partial retirement from the ATC.

She was apparently well briefed by Eileen about what I would ask:

*Jan: Right OK, Eileen the first time we met what did we talk about?*

*Eileen: We talked about the life, you know.*

*Jan: Your life, yes, so I was hoping that's what we could do tonight, Beryl, talk about you and your life.*

*Beryl: yeah well I started at Bramingham when it first opened, just before that me mum died..*

### *Autobiography*

Beryl was born in central Luton in 1932. Her father worked in the dye works, her mother was 'a stay at home'. Her father wouldn't let her mother work 'that's how it was in them days'. Her mother had brought some hat work home once but her father made her send it back. Beryl contrasted this with the ways she was brought up:

*I been brought up with a mind of me own ..when me dad were alive he let me handle me allowance. I always had to draw it meself. He said I ain't doing it for you. It's yours, so you collect it.*

She recalled only one event from her early life:

*Learnt meself (to walk) walking along the furniture, all that, yeah .. I learnt to walk didn't really do nothing till I were 7 year old .. I had lessons at home ..I didn't walk, didn't walk till I were 7 .. I had trouble, bottom of me back, it stopped me walking .. I didn't used to go out, weren't no Centres then.*

Chronologically the next events she mentioned followed the death of her father (in 1961);

*Ooh, me dad died five years afore. It was after me dad died me mum got rheumatoid arthritis. I had to do housework, cooking, she couldn't get out see, we lived on a hill, top of a hill, she got rheumatoid arthritis in her knees .. except when me brother fetched her, fetched her in the car she never got out .. I mean she was 'ousebound .. my mum was very ill, cancer .. I knew it were coming.*

Like the other interviewees who 'looked after' older parents (see Chapter 7), Beryl

described this in terms of concrete household duties - shopping and cooking.

In the interview Beryl actually began her account with events from her life around the time of her mother's death:

*Yeah, yeah, then me brother said he were trying to fit me in, I didn't know where I were going at that time. This Centre that opened he heard about it so he got me in there .. see my brother who lived in Shefford he kept an eye on me. I used to live in a house on me own, after me mum died he keep an eye on me..I went with me brother for a time. That didn't work. He married to his first wife then. She wouldn't accept me sort of thing, so he helped me along then he got me back in me own house that were me mum's house, he got me to live up there he used to keep an eye on me, see I was alright .. the Centre, it were opened in March that year, I didn't go till after Easter .. her (mum) died in January . When I were going to Bramingham he let me go back home .. he only had me a short time, he wanted to have me permanently till I got over..*

Her brother ('he were a good brother'), died aged 54, and at that point she left her old family house and moved into her flat in a large block in a North Luton Council Estate:

*Then I sold that, see before my brother died they wouldn't even think about me getting a flat. They said it wasn't unsuitable, me brother said it was, they wouldn't do nothing till me brother died, then they do something for me.*

That was the last major change described by Beryl, though her retirement was about to happen.

## Analysis

### *The family*

According to this account family played the key role in Beryl's life until the death of her brother. The way she told it, it was natural that she would stay with her parents, and take on the job of looking after her mother. She 'didn't want to go out'. She talks of her brother 'keeping an eye on her' when she lived alone in the family house. Although her brother briefly gave her a home when her mother died, she said that it was never intended to be permanent, and she linked the opening of the ATC within months with her brother agreeing to her going home. Looking after her mother in her last years seems to have been a source of satisfaction.

Since her brother's death in 1985 family has faded:

*He (brother) got some nephews by his first wife, don't see the youngest one hardly at all. Oldest one sends me cards on me birthday. Youngest one got a boy of his own now, a year old, never seed it .. I got some cousins down Devon way. I learnt all the telephones since me brother died. His second wife, she remarried, don't see her at all.*

### *The impact of services*

Beryl's life neatly illustrates the impact of services. She was probably certified, as she did not go to school, and says she was visited by a home tutor. Her description of teaching herself to walk when she was 7 suggests the absence of medical interventions. Her uneventful life at home until her thirties has resonance with the archive evidence, particularly the Voluntary Visitor's records (see Chapter 5). Her account of events after her mother's death points to the importance of the Centre because she links its opening in the same year with her brother accepting her living in her own home. At the ATC she learnt to cook:

*I didn't cook much till I went to Bramingham, a lady called Mrs. Hayes, she taught me a lot, I learnt lots since I been there*

Currently, however, the ATC seemed to have little to offer her:

*We ain't got nothing .. nothing, we ain't got none work for months and months. Years ago we got all sorts of work. I don't need to learn cooking really .. what good gardening? I ain't got a garden. Even when I were younger I didn't do it.*

The provision of a flat only after her brother's death ('see before my brother died they wouldn't even think about me getting a flat') shows the local authority acting only when the family could no longer provide even minimal support. Then she was retired, attending the Centre only two days a week and perhaps, like Edgerton's older people (1989), living a lifestyle less atypical of other women of her generation than she has since early childhood.

Beryl was aware of the historical context of her life. Remarks such as 'weren't no centres then' which she used to explain her life at home show a degree of knowledge of the wider context of her life lacking in most of the interviews.

Yet Beryl's story is also untypical. By virtue of her own competence and the twin chances of having a 'good' brother and the opening of the Centre just in time she remained in the community throughout her life, and had never experienced residential care. As Chapter 5 shows, this was relatively unusual in the post war period.

#### *Identities around Gender, Caring and Dependency*

Beryl never openly spoke of herself as a woman with learning difficulties. She used terms such as 'people like us' when it was necessary to provide an explanation. She knew she spent her time in places for labelled people. As she said:

*We got another handicapped girl at the Centre, well she would have*



*been normal.*

There is no doubt in my mind that Beryl knew she had been labelled and dealt with accordingly, but this does not diminish her. Her narrative was one in which she appears as an actor, someone who makes decisions, and who makes the best of things. She was happy to be at home with her parents, pleased to look after her mother, looking forward to retirement ('I'll go out and about. I won't sit in. I ain't one of those what sits in'), and only a little resentful of the family which had turned its back on her.

Beryl's concession to being a dependent person in social terms was limited to acknowledging that her brother and staff at the Centre 'keep an eye' on her. The main area where she needed practical support was in writing cheques - she cannot read or write.

Close relationships with men, other than her father and brother, were non-existent as far as Beryl's account went:

*Jan: What about you, Beryl, have you had any boyfriends?*

*Beryl: No, don't want one.*

No more was said on the subject. Beryl expressed a caring female identity through cooking for her friends, helping Jane look after her flat, comforting Eileen when she was depressed, and making her 40th birthday cake.

This was well illustrated through her relationship with Jane (43), her neighbour. Beryl knew Jane through the ATC before she went into hospital in 1974, and resumed friendly and neighbourly contact when Jane moved into a flat three doors away, quite by chance:

*I got another girl Jane she sees me a lot ..you wouldn't miss her, she a big girl, she's fat .. she come and have meals with me*

Beryl told me that Jane had wanted to cut down her days at the ATC when Beryl retired, but they wouldn't let her because it would be too great a burden on Beryl: 'They think it's too much for me'. Beryl made sure I knew that Jane had difficulty keeping her flat in good order. Jane told me:

*Yes she does help me, sometimes she comes round and helps me clean up if I'm not very tidy. I asked her to come (to Review at the Centre), just be there and tell a bit about me .. she said good things about me.*

In fact, with Beryl's help a home carer and more hours at the play group were agreed at the Review. Beryl adopted a parental style when she joined my first interview with Jane:

*Beryl: Didn't settle nowhere did you? .. when she was young she didn't settle at nothing .. she can read, she can write so I think she could done a job if she played her cards right. I speak up better for her than she speak up for herself.*

*Jill: I did speak up for meself a bit didn't I?*

Within the ATC Beryl had a place of some significance. It was her public arena. She was on a User Committee:

*Yeah, well we talk about all what happens 'bout each other, 'bout doing the coffee room up, all sorts .. we did a lot of good things, got some money for doing the room up, the 'andicapped. We got 900 pound .. we wrote to the mentally handicap (?MENCAP) they sent a hundred pound.*

Beryl was well informed about what went on at the Centre, and had insight into its practices. For example, when we talked about boyfriends she told me 'they stop it a little bit. One girl, she got sent to Silsoe so she lost her boyfriend'. In the same way

as she provided a commentary on Jane, so she did on the Centre:

*Some come back (from work at the horticultural centre), some have gone. They do two years, then they come back.*

Of people helping in Special Needs she said:

*Somebody have an accident, one of the staff over there, he broke 'is, he cracked 'is rib, yeah that's when they stopped doing it .. they stopped Eileen .. so they have to do it themselves.*

Overall, Beryl presented herself as robustly self sufficient and independent. Deprived by the circumstances of her life of conventional female adult roles - worker, parent, sexual partner - she created her own caring roles in relation to mother, friends and other service users.

## **Bert**

### *Interview situation*

Bert lived in a mixed sex ward in Bromham Hospital. I was introduced to him by the ward sister, Pauline, when I went to interview two other people named by the Consultant Psychiatrist who had given me formal permission to interview hospital residents. Pauline recommended Bert as someone who had an interesting history, who was available and who was able to communicate. She found him, ushered him into my presence, and we began. He had no forewarning, and no chance to say no. I described him in my notes as 'a bright looking chap, short and dressed in a blue shirt with a round necked blue T shirt under it.'

### *Auto/Biography*

Bert was born in Luton:

*I didn't go to school, didn't go to school till I was six, and I wouldn't learn, they sent me to a backward school but I never used*

*to go. I didn't like school.. I shoulda learnt reading at school, but I couldn't concentrate. All me mates was brainy they did National Service, all me mates that was at school with me.*

(Bert was put under 'friendly supervision' when he left school at 15 according to the Minutes of the Mental Health Sub Committee, 10/53.)

The great regret of his life seems to have been that he did not join the army like his father and brother:

*I didn't pass entry for me National Service, so I went to see if I could join the Regular Army and I passed me intelligence test, I was Grade 3 .. I was doin' all right in the Army I liked it.*

He said he was discharged because his feet bled.

He trained as a plumber, but couldn't pass his apprenticeship because he couldn't read, then got a job:

*On the buildings .. hod carrier, hod carrier, that's my trade.*

That didn't last, he was 'on the dole' and then committed the offence which first got him into hospital:

*I was at Magull, I was at Magull then, like Rampton. I did six years there .. I done housebreaking, picked up with the wrong lads, wrong crowd, an't I, mixed up with the wrong crowd, yeah .. I went to Leavesden first time, though when I got in a bit o' trouble. I think it was a factory break in, somebody shopped us, I got taken a year, I did 6 months, I got parole, then I run away and I got a job on the buildings and I kept outa trouble, then a second time I got in trouble again, I went to magistrates court in Bedford Assizes, we can't send you there cos you run away, you kept outa trouble we coulda discharged ya, they sent me to Magull for six years .. I came straight*

*from Magull to here, they told me you done your time and you've lost your mother, we'll send you to Bromham you know .. if my mum had been alive I'd have been out, yeah.*

Bert said he'd been in Bromham for 20 years, though he wasn't sure: 'Pauline'll tell you how long I been here, good while now'. It was hard to be certain of his age when he'd first been put in hospital, but I calculate he was in his 20s. He was then 55.

He described Magull:

*Hard life, I've had a hard life .. well they used to boot them, put a strait jacket on and boot them in the side. They didn't boot when I first went there, they just boarded up, you know, but I was told Rampton was worse .. I got on with the screws alright there, though .. I had a good report there .. A State Institution. State. High walls like a prison you know, and I worked in the boot shop for a while, didn't like it, making me bad, then I see Dr. Webster. I said can I go in the gardens, he said yeah, they put me in the gardens and I worked on the gardens ever since till they sent me to 'ere.*

Bert was tearful when recalling his mother:

*It was a long way for me mum to come and see me though, 'bout three pound 15 on the train, yeah. She took bad and died in hospital she did, yeah .. me youngest brother lived with her then, told me what happened, and he tried to get me out for the funeral, but the chief wouldn't let me go there, the chief what belonged to the hospital. I was bad for a week though when mum died, I was upset.. I hadn't seen her since she was alive, since I was at home.*

*Family*

Bert's mother had been the most significant relationship in his life, and her death may have been the most important event:

*If my mum had been alive I'd have been out yeah .. I loved me mum.  
I didn't like me dad. He liked his old beer you know, a boozier, yeah.  
They separated, he went with another woman you know, he use to  
send her money. I didn't like me dad best, I liked me mum best.*

He cried when he told me he wasn't allowed to her funeral.

Bert's brothers and sisters feature a lot in his conversation, particularly Don, his youngest brother 'he got a good marriage, Don has'. Don has cared for Bert. It was he who tried to get Bert to his mother's funeral, and Bert stayed with Don in his brief period out of hospital. He hoped to work with Don when he left hospital:

*I was gonna work with Don, plumbing, he done four years  
apprenticeship, Don has, he done four years, he's self employed.*

Don's comments on Bert's life are recounted; 'Don says you still coulda learnt though if you went to school at 6', 'Don says 'bout time you got married', 'Don says you oughta go and see her (sister in America)'. The idea that family will provide support continued to give Bert hope.

### *The impact of services*

It seems that the practices and beliefs prevailing in the late fifties, at the time Bert was put into hospital, had shaped his life to a marked degree. Over 30 years later he was still in hospital, though seemed no less able or competent than most of the people I interviewed who lived in the community. He had the twin misfortunes, of being labelled a man who required 'friendly supervision' on leaving school, and of having no parent to return to when his sentence ended.

Bert was soon likely to be discharged into the community. Bromham was due to close in 1996, so a change was imminent. He had already tried one place which, he

said, he chose to leave and return to hospital because he did not like one of the men sharing the house.

*Identities around Gender, Caring and Dependency*

Unlike the women described in this chapter, Bert did not appear to frame his identity either around caring or dependency. He did not describe himself as handicapped. He made oblique references to going to a 'backward school', and described the hospital where his girlfriend lives as 'a place like this', but that was as far as he went in acknowledging that he was in a mental handicap hospital. By contrast, he readily owned the criminal identity consequent on his misdemeanours, talking of 'screws', 'parole', 'like a prison'.

Bert presented himself as a man who makes his own decisions. He'd recently lived briefly in a flat in a town near Luton, but it hadn't worked:

*Gordon Michael, he started swearing at me you know so I come back to Bromham. Ain't gonna work if you fight all the time. I keep to meself 'ere. I can always watch the telly upstairs. I got my little room here, not a side room yet though, I just keep to meself.*

The practice of distancing himself from the other hospital residents was recurrent:

*When they hit me I hit them back, see I done a bit of boxing. I trained to be a boxer.*

His friends were not other residents, but staff:

*Jan: What about friends here. Do you have any friends here?*

*Bert: I like Sister Tomson, I like Martin when he's on, Pauline's alright, I get on with the nurses .. patients talk to me like a bit of dirt.*

He was a trusted patient, allowed to cycle into Bedford and surrounding villages

when he wished.

An important part of his identity was as a worker. He told me about his work in Magull, and in Bromham:

*I've had three jobs they been good jobs. I worked in the laundry six years, then I come out there I went home for a while, got a job out at Leagrave (ATC), I used to live with me youngest brother Don, I got one pound fifty, I got bored with it, then I come back, then I got a job in the TAC (Hospital Workshop) four years, I come out there, then I worked with George, the porter you know, the coloured bloke .. I'm a deputy porter you know with the dinner trolleys.*

Bert expressed his masculine identity quite forcibly. References to being in the army, to boxing, to looking after himself amount to a particular stereotype of maleness. This had its poignant side in relation to his romantic interest in nurses. He said:

*I like Simone, though, what's on today, she come back again, now she's leaving again. I wanted her to come to the flat with me, she couldn't come cos she's a member of staff. I says could she live in? We get on alright.. She (Maggie) was a nurse here. Few years ago I went to see her and ask her to come back, she said I like to come back for you, but she's going to Greece but I was sweet on Maggie, hair like Pauline but all ginger hair you know, all down her back.*

Mike told me he and Bert looked after the nurses and chased women together:

*Me and Bert, every time they have a fight, me and Bert try to calm them down, if they don't calm down we go in the office and fetch a nurse .. Me and Bert's always chasing the girls round the blocks, me and Bert's a right old girl lover.*



I saw Bert's relationships with female staff as an attempt to negotiate the difficult issue of being a man dependent on women carers. In his conversation he made them into prospective girlfriends, or into the recipients of his and Mike's chivalrous protection, both traditional male roles.

Bert also had a girlfriend, a young woman he met on holiday:

*There's the girl I met. She comes from Stoke on Trent .. she wants me to go over and see her but it's too far for a day, Stoke on Trent. She wanted me to go back with her. Don says 'bout time you got married. Nice girl, though, nice girl.*

At our second interview Bert updated me:

*I had a letter from that girl again she's got two on the way at the moment. Yeah I writ her a letter asking what she'd like for Christmas. She likes music, but I don't know what sort of music she likes, yeah .. Yvonne her name is. She's in a place like this, but she isn't allowed out in the grounds without a nurse.*

This suggested a longing for a traditional protective male role in relation to women (Edley and Wetherall 1993), one he had very limited opportunities to perform.

## **Lynne**

### *Interview situation*

The local MENCAP secretary told me about Lynne as a woman who cared for her father. A lengthy attempt to make contact ensued. I was helped in this by Rita, the Sheltered Placements Officer whose job was to look after people with learning difficulties in work. She tried to arrange an interview at Lynne's workplace and failed. In the end we met at the hostel near Lynne's flat. At Lynne's request Rita was to be present.

[At the hostel I was introduced to the Officer in Charge who had known Lynne for 20 years. She told me Lynne's father, like many others, had difficulty accepting self advocacy. Lynne's sister, she said, 'doesn't do much', and Eddie, Lynne's boyfriend had been harassed by Lynne's father, for example, ringing him up to do errands when Lynne was unavailable. Staff had stepped in to defend Eddie.] All agreed that Lynne's father should not be told about the interview and helped Lynne rehearse a story about visiting a friend there as a reason for being out that evening.

### *Auto/Biography*

Lynne was 43. She was nervous 'I don't know what I'm going to say tonight'. In fact, she was reticent about the past, and the facts are briefly recounted.

She was born in Luton and once lived 'up Farley Hill'. With difficulty I elicited the information that she'd been to Ridgeway (an Occupation Centre opened in 1959). (The Minutes of the Mental Treatment Subcommittee dated 12/9/57 record that she was put on statutory supervision at the age of 8). She said firmly it was a school. She later went to the Centre, from where she obtained her job. Her mother died:

*I was down the Salvation Army when she died and dad had to go up the hospital with me uncle and it was too late so someone told me down the Salvation Army. On the quiet before they gave it out .. she'd got cancer .. she kept falling over and I went to work.*

She was unable to give any indication of when this happened. When pressed to give details she did not want to recall she changed the subject. However, it did result in her father taking over the cooking in the family, something that Rita referred to more than once when arguing that Lynne owed caring obligations to him.

The only event which was dated was her starting work:

*Been there 7 years, nearly 8 years .I wanted a job. I worked in C and A for a month's work experience and me dad said there's a*

*factory up near where he works.*

She said her social worker had found the job, [though Rita said it was the Pathway officer].

### *Family*

Throughout her life Lynne had lived with her family. Her mother died, her sister left home to marry, and she remained. She began the first interview saying:

*I know I'm not very happy at home at the moment .. I'm a bit fed up with me dad. He doesn't know where I am tonight. He thinks I'm going round a friends. I daren't tell him.*

Fear of her father, and dislike of living with him, were recurrent themes, a graphic illustration of a care relationship which was felt to be burdensome and restrictive.

It took some time to ascertain the precise nature of the tasks Lynne did for her father. Rita questioned her persistently to discover what these were. One was shopping:

*Dad writes a list out and we have to get what he wants. He likes his stew and dumplings and I don't.*

Lynne handed her 'board money' to her father and he gave some back for his shopping. Money was a matter of contention:

*Well every Thursday night I usually give him me board money. I didn't this week cos I didn't draw me money out till Saturday. "Where's me money, where's me money". I give up. He wanted his money for shopping Friday night, I think. He didn't know we was doing it on Saturday.*

Other than shopping, Lynne said her work in the home included:

*Cooking his dinner and washing up what I normally do.*

Lynne prepared her father's dinner the night before, and left it ready for the home help to put in the oven. She had to monitor what he ate because of his diabetes:

*He's only allowed potatoes when he doesn't have stew and dumplings cos of his diet.*

She peeled all the potatoes for the week on Saturday nights.

She said she spent little actual time with him:

*Jan: You scared of him?*

*Lynne: I am I'm always in me bedroom. Part from tomorrow. I goes to the Club.*

*Jan: But you don't actually spend any time with your dad?*

*Lynne: No.*

*Jan: Is that, do you choose not to?*

*Lynne: I have me dinner with him. Sometimes if it's hot I have to wait for it to cool down.*

*Jan: But you don't sit and talk to him at all?*

*Lynne: No.*

*Jan: Would you like to?*

*Lynne: No, I'd rather go out.*

The tensions in the relationship came to a head in between our two interviews. Rita brought the subject up, and Lynne said she'd prefer Rita to tell the story:

*The way I understand it is that dad was having a go at Lynne and Lynne lost her temper. She was peeling the potatoes. And she waved the knife to her dad. So he told the home carer and the home carer fetched the social worker.*

Lynne corroborated this and said:

*I wouldn't really do it. I was upset at work wasn't I .. he was going on .. he said do something while I was peeling the potatoes .. he (social worker) said he'd put me away next time .. social worker said to me dad you won't be staying here, you'll be going a long way away .. he said if I tried that again to call him, he said I won't be in Luton .. I heard him*

This incident summed up Lynne's situation with her father, and her social worker. She felt that her father asked too much of her, that he tried to stop her going out, and that the social worker was on her father's side. It was perhaps unsurprising that she wanted to leave home. She was a single daughter at home with an invalid father, and worked a double shift, at home and at a full time job, yet remained infantilised by her father, a view shared by staff at the hostel.

#### *Impact of Services*

Lynne's career until she got her job seems to be fairly typical of a woman of her age who was certified as ineducable, and whose family were prepared to take responsibility for her: certification, Occupation Centre, then Training Centre. There are many examples of such a life course in the records of the Mental Treatment and Mental Health sub committees.

However, what is missing from these written accounts is the subjective meaning of such a biography. She did not mention the process of being certified. Her reference to Ridgeway Occupation Centre as a school reflects, perhaps, an attempt to normalise her situation, or possibly, the well meaning efforts of family and staff to do so. The importance of her job was reflected in the fact that this was the only event she was able or willing to give a date to. Even the means by which she got the job was presented as a family initiative, not an intervention by MENCAP's

Pathway, a specialist job finding service.

Getting a job set her apart from all the people I interviewed, and made her situation uniquely complex. I examine this below.

### *Identities around Gender, Caring and Dependency*

Lynne seemed to have three distinct social identities: an employee; a woman with learning difficulties; and an unpaid carer.

Lynne talked of her work at a pharmaceuticals factory with pride. She washed her own uniform, got herself up and off to work by rising at 5.20 every morning. As an employee she spent her working day in the company of non disabled people with minimal specialist support. The Company were, according to Rita, anxious to treat Lynne as any other employee. Some interventions, such as Rita's visits, were accepted, and there had been special efforts made to ensure she was well fed, and that her wages were accessible to her. But it was not sheltered employment. Lynne was expected to pull her weight, packing drugs, with the other workers. She herself made reference to this.

Possibly as a consequence of her status as a working woman Lynne had more casual community contacts than many I interviewed:

*I get me money out in town now. .. If I want a prescription I ask sometimes the Library to do it for me .. I go in the Estate Agents next door too, I still pop in to say hello (this was where she used to draw her wages), Thursday nights I still go down to pay me rent.*

The need and the opportunity to meet people in the course of running her life seemed to give Lynne confidence in these transactions. It was an obvious benefit of her employment.

However, she remained a person with learning difficulties in many respects. She did not acknowledge this openly, but it was clear from her social contacts that she

was still part of the network. Service providers lingered in Lynne's life from her days as a client. The Officer-in-Charge at the hostel where we met knew Lynne well. She had contact with professionals through Eddie, still a user of services - for example she was anticipating going out to eat with Eddie and his key worker. The one worker who currently had responsibility for Lynne was Rita. Lynne appeared to trust her as she insisted on her being present at both interviews. Rita assumed the role of co-interviewer, and used the opportunity to pursue in some detail those areas which concerned her as Sheltered Placements Officer - Lynne's diet, her health, her teeth ('I think you're having trouble with your teeth you know. They're falling out all the time').

Lynne's leisure time was largely spent with other people with learning difficulties. She went to the Club on Wednesday evenings, and on the outings organised for its members, she went to the gardening classes at the hostel. Above all, she knew people. This network, shared by Beryl and many others in the sample, was long standing and durable. Its significance was illustrated by an incident at the hostel. I had brought a gift for Rita and while we awaited her arrival a hostel resident tried to grab it. I could not cope with the situation, but Lynne said 'Sit down David' and he did. Later we talked about the incident. Lynne said she'd known him from the Centre and he used to talk 'but now he don't'.

Lynne was also a carer, for her the least welcome identity. This entailed relationships with a number of professionals who were there for her father. He had home aides and home care assistants coming into the home, including at weekends. It was a home care assistant who called in the social worker after the knife incident. Lynne had mixed feelings about the home care assistants:

*Sometimes Dora comes at weekends. She's alright. She does say hello to me .. But sometimes I just want to keep out of the home care's way and go out.*

In this respect, her home was the site of someone else's care, and this compromised her autonomy within it (Gavilan 1992).

Her caring role was most complex in relationship to the social worker. He was Asian and she claimed to be unable to understand him. There also seemed to be a greater difficulty; he was both her father's social worker and hers, (unlike Alanna who had one for herself and one for her son), and they had different and irreconcilable interests. Lynne was keen to leave home and live on her own 'before I get too old'. The social worker may have been the key person to achieve that, but their relationship was such that she could not imagine making contact with him to talk about rehousing. It seemed that for the social worker she was part of her father's network of support, not a person with needs of her own, a classic conflict of interest.

As an adult daughter at home Lynne was under pressure to take on the role of caring for her father. This was clearly articulated by Rita who told Lynne that the fault in the relationship was not one sided:

*I think sometimes dad gets cross cos you aren't doing the things you really should do. Cos you just want to go out. Am I right? It's not always dad's fault he gets cross is it? It's sometimes your fault .. Well I say to Lynne sometimes that hard as it is for her to have to have someone like dad dependent on her to a certain extent he took care of her when she was young and helpless and needed someone and now she is grown up and able to cope in life she should help if she can.*

It is a clear exposition of a commonly held view on daughterly obligations to elderly parents, though some of the language ('now she is grown up') seems inappropriate for a woman of 43.



Lynne also had a boyfriend, Eddie. She met him at the ATC and they had been friends for 13 years. In answer to a question from Rita she said he had asked her to marry him, but she'd said no because he was too old. It was not described as a sexual relationship, but it did give both practical and affective support. He did the shopping with her and they met most days after she'd finished work. She described how he made sure she ate:

*Eddie took me straight down town to have two beef burgers. I said "Eddie I only want one beef burger". "You're having two, you got to eat".*

Eddie had been banned from Lynne's flat because her father was trying to get him to run errands for him.

Lynne was exceptional. Beryl told me she was the only person from the Centre to have got and kept a real job. But this change in status was in some ways superficial. She still did not enjoy the autonomy that having her own income might be expected to bring. Her father, according to her and others, still treated her as if she was a dependent, took 'board money' and expected her to obey him and account for her movements. She was expected by him, and others, to carry out daughterly obligations, and her wish to be an independent householder was not taken seriously. In terms of care, she was both carer and cared for. The formal care she received was very much geared to sustaining her ability to carry out her job. Rita was responsible for overseeing her health - food, spectacles, teeth were all matters of interest to Rita. The care work Lynne did for her father was actually quite substantial, but she got little credit for it and no rewards. Her history as a woman with learning difficulties had followed her into the world of work. The consequences for Lynne were that she uncomfortably straddled two worlds, and had few of the benefits of either.

## **Alanna**

### *Interview situation*

Alanna was one of four mothers located for me by the local special needs Adult Education tutors. She was described as 'very nervous' by her tutor who offered to sit in on the interview. Alanna refused, saying 'we'll see how it goes'. We met twice, on both occasions at the Church Street Centre on the afternoon Alanna goes regularly for her literacy class.

Alanna was concerned about the tape recorder, and about confidentiality. She did agree reluctantly to have the tape on, but refused my offer of a copy afterwards. Instead she received a written account which was amended and expanded at the second interview.

In my field notes I described her thus:

*She is a small tidy woman, carefully dressed. She wrung her hands a good deal, and clutched the table a lot, but occasionally let go and gesticulated.*

Unlike Beryl, Alanna was not fully briefed beforehand:

*Jan: Can you tell me a bit about yourself*

*Alanna: What do you want to know?*

In fact we began by discussing her son, John, as he was the obvious reason for meeting her.

In telling her story Alanna exercised control over what she was willing for me to know.

*Jan: How old were you when you had John?*

*Alanna: I'm not able to tell you that.*

*Jan: How old are you now, do you mind telling me how old you are now?*

*Alanna: Not exactly, I'm in me thirties.*

Certain details of her schooling were (deliberately?) obscured. For example, at one point she said:

*Mum tried me at the proper school first and I was a bit too slow so then I went to Richmond Hill (special) School and I was better than them.*

Later she said:

*Well first of all I went to Richmond Hill School but that was the school where I seemed to be the best, then I went to an ordinary school, too slow for that.*

I pointed out the discrepancy in the second interview in going through the 'story'. She apologised, and said the first version was correct. It is unclear what prompted her to tell me two different versions, nor whether there were other instances which I did not notice.

Of all the people I interviewed Alanna was the one who most obviously used the interview to confide intimate details of her sexual history and her feelings about her mother. She said after the first interview that it was good to know she could say all these things but 'mum would murder me' if she knew she'd been telling anyone. I link this to her care to ensure that the interview was confidential; and to her experience of confiding in her social worker.

*AutoBiography*

*I was born in Ireland only I been in Luton a long time so I probably lost my Irish accent .. in those days Ireland was a lovely place, it*

*was all nice .. the people are very friendly, not like here, well most of them are but it's sometimes because the men are drunk.*

The family came to England when she was three. Of her father she said:

*He works for hisself, and he used to work at Vauxhall I think and that didn't last very long I don't think he likes being bossed about and that.*

She initially went to local schools (see above), but was later sent away to school on the south coast. She said it was a school for all kinds of girls with 'an illness that didn't show', and at another point said:

*Me mum only did it for me own good because of me dad being drunk all the time and swearing and cursing and that she didn't want me growing up that way she did it for me own good.*

Alanna mentioned later:

*Once he hit me and he said he'd never do it again. It was only cos I couldn't get me own way. He hit me cos most probably I was playing up.*

She enjoyed the girls school on the south coast:

*All the girls and the walks in the evenings and that kind of thing, it was very nice.*

The fact that it was all girls was appreciated. Later, she was sent to a mixed boarding school at a town near Luton:

*In case I got told off, I was always afraid of that school, that was a problem with me learning .. I hated it I really did, one teacher there that was strict and made me more nervous than I really am and when people make me nervous I'm just not able to do anything you*

*know, like reading and writing .. I mean when we came home for a holiday cos I didn't want to go back I hid meself in the wardrobe at home and mum of course was worried she couldn't find me anywhere.*

She left school at 16 and went to work:

*See me mum got all the jobs for me because you still had to write forms and be able to talk to people and explain see I could only do certain things like washing up, cleaning all those kind of things.*

She had two jobs she could remember, one in a hotel and one as a hospital domestic: 'If it was a men's ward I didn't get on very well cos I used to be shy kind of thing'.

Around this time she said:

*I always wanted to go out, didn't have many friends to go out with, so mum only kind of took me to the pictures kind of thing, you can't do much with your mum there with you kind of thing .. that's when I used to go out on me own when I was at home you know and got meself in um [pause] trouble .. you see this is where I wandered away from home like to these kind of places on me own and that's how I got into trouble a lot .. I regret being with the coloured person now cos I know it was wrong to be going out with a coloured man and I fell pregnant with him and I had to have the child killed which I don't think I liked, I mean to kill a human being.*

She found another boyfriend:

*We used to do it in different places and not always the right place and he was in a hurry the last time we did it like he wanted me to have John and just go like, not be bothered any more .. didn't want*

*me any more which I was kind of sad and crying me eyes out.*

John was the child of this union.

Whilst she was pregnant:

*She (mum) came and got me which I regret, see I was at a friend's house and they were letting me stay for a while you know, but I think I would've been able to sort it out but me mum and dad come to the house and brought me home, they didn't say anything, they were very quiet, but I regretted it because I didn't want to go back home .. at the hospital I had John, then I went to a place where I met more nuns, a place to know the baby a bit more and how to handle them and wash clothes .. then I was brought home to me mum and things didn't go too well there cos of me dad being the way he was with John crying, mum and me had to keep him quiet, if he woke up he'd be shouting .. I stayed with me mum a couple of years then mum wrote away for me cos I still couldn't fill in forms . Then I er went into a flat . Then after that mum found a house for me, it was only just across the road.*

John was 15 at the time of the interview, but no major transition points emerge in Alanna's account after his birth and moving into her house when he was about four years old.

### *Family*

Throughout her life Alanna's most significant relationships had been within the family. The two major relationships in Alanna's life at the time were with her mother and her son. They were intimately intertwined. Alanna regarded John as having been her route to independence from her mother:

*I think I'd be worse now if I didn't go out, then I'd be very quiet and*

*by meself always washing up at home, always doing things for me mum. .. She's not strict or anything but I think she'd like to keep me in my place.*

Her bid for independence was only partially successful. Her parents reclaimed her when she was pregnant, against her will.

John was 15:

*He's just got a learning difficulty, he's not able to read or write, you see it's like meself when I used to go to school, I couldn't learn.*

She said it was a struggle to bring John up:

*He's very strong, he's a big lad, he's hard to manage, he get annoyed at you when you tell him what to do. He's lovely really, it's just that he's very hard to cope with.*

Alanna seemed to lack confidence in her mothering. She made uneasy comparisons with other children:

*I don't know if an ordinary boy would get up, wash himself, see I don't know if boys of 15 gets their own breakfast or does their mum get their own breakfasts .. well specially her, the one across the way, she's young and she got four kids .. one's a baby, she can cope with that too.*

There was a constant theme of getting it right:

*You see as well as me being nervous I'm very shy and usually very nervous if you see what I mean and I suppose that doesn't really help John. When he comes home in the evenings we don't really have a chat, a nice chat, he won't really sit still for me to talk to, that's where he misses out.*

Whilst her mother had been on hand throughout, Alanna was less than enthusiastic about the help she gave:

*He will do what he's told for her, for me mum like, it's just that she don't like to look after him.*

It wasn't until the end of the second interview that Alanna revealed the extent of her mother's influence. She told her what to say when she went to meet John's teachers 'drums it into me', and finally, she said:

*Yeah, well she thinks that I can't cope .. I've always got the feeling that me mum is putting John down a lot, I mean she'd like him to go to this other place where they look after him and that .. like have parents to look after him, like a mother and father.*

Alanna's mother's efforts to help undermined her confidence. Alanna summed up the situation when I asked her what she wanted from the future:

*I think other mothers let their daughters do what they want to do and I think I'm a bit left behind if you know what I mean, I'm doing what me mum wants me to do, maybe she thinks I want to do the things I did years ago, but it's not the case, not now .. Mum says I'm moody a lot of the time, I don't think I'm that bad, I think it's because I can't tell her what I think.*

The three way relationship between Alanna, her mother and John encapsulates continuing tensions in a long term caring relationship. Alanna believed that she hurt her mother, and tried occasionally to excuse her; she was ill with sugar diabetes and she admitted 'At times I must have killed me mother.' There were signs that Alanna would move into giving care to her mother as she grew older. Already, she looked after her dog. Yet continuing semi-dependence on her mother for such things as form filling seemed to deny Alanna the sense of adulthood that might come with



being the mother of a teenage son.

Her parents were separated. Her dad was a heavy drinker, and fear of him was a thread woven throughout, mixed with fond indulgence: 'He's a bit like John really, a bit of a child'.

She had two brothers, one of whom used to take her out:

*Brother used to take me out to a pub and there was singing and all that, but I mean the money ran out and we can't do it much any more.*

Then she rarely saw him:

*I know where it is, it's just like he's always busy and when he comes home he's tired .. he most probably doesn't feel like visitors.*

The other brother lived in Australia.

That Alanna was aware of the limitations of relying on family emerged at various points: 'I used to like dancing but got no one to take me dancing'. It was lack of friends which drove her to go out alone in her teens. Then her mother was her companion on shopping trips and the like, 'apart from that I'm on me own kind of thing'. She attributed this lack of friends to shyness:

*I never was any good at joining in even when I was at school .. I always have to have a whiskey before I go out anywhere.*

This was one of many references to what she regarded as a crippling shyness.

### *The impact of services*

Of the four people in this chapter Alanna's life appears least affected by learning disability services. Other than through schools she had had no contact with the sorts of services - hospital and ATC - which have been significant for Beryl, Lynne and Bert. I made contact through adult education, not social services or MENCAP. It

may be significant that she was born at a time when control of sexuality was less paramount in the minds of the authorities (see Chapter 5).

Perhaps partly for this reason, Alanna was one of the people who spoke most glowingly of service providers. She and John each had a social worker. The importance of this was apparent:

*Now that Diane comes to see me once a month I can get things off me chest. Before I didn't have anyone to talk to except me mum, and it used to upset me mum and she didn't have anyone to talk to except the doctor .. before I had her I used to be depressed and crying a lot, but now she comes once a month I'm much better.*

John's social worker, Ivan, advised her on parenting, and was helping to think about John's future, whilst Diane was there for her. Diane was referred to as a friend, and friendship carried social obligations:

*She's a good friend you know, she's somebody I can tell everything to, she'll keep it to herself. I hope it doesn't drag her down too much, poor thing .. she's had a bad time of it this last year, too.*

Although Alanna was a long term resident of Luton she had none of the relationships with peers which characterised Beryl's life. This threw Alanna into dependence on her family and social workers for support and companionship. She attributed this social isolation to her personal characteristics, though the absence of day time occupation outside the home may equally have been the cause.

#### *Identities around Gender, Caring and Dependency*

Alanna aspired to be a good mother. The identity 'mother' is what drew me to interview Alanna, and was salient throughout the interview. Foremost identities for her were mother and daughter. As a mother she was a (willing) carer. As a daughter she was an unwilling dependent, despite being a householder who controlled her

own income. She herself identified why she had remained so closely tied to her mother. Her mother's personality; her own learning difficulties, particularly filling in forms; and her shyness and nervousness. The continued day to day involvement of parents well into adulthood was not uncommon in the group, especially women, and Alanna was able to articulate her ambivalence over this continued emotional, and, to some extent, practical dependence. The existence of a son with learning difficulties, seemed to have tied Alanna to her mother, as well as giving her the chance to escape life at home. She ruled out the possibility of a job: 'I don't think I'd be able to do a job .. cos it's been a long time since I had a job'.

Mixed with this was a fear of men which she said was in part the reason for her shyness and isolation:

*Even coming here is difficult, most of the time me head is down on the pavement, I'm afraid to look up.*

My sense of Alanna was of a woman whose lack of confidence was more significant than learning difficulties in limiting her opportunities for autonomy. Her mother appeared in Alanna's account as someone who has exploited her 'learning difficulties' to keep her emotionally tied to her family of origin. Alanna's narrative showed a sensitivity to her situation which was unusual in its articulacy. The interviews were for me a moving experience; and Alanna was on both occasions reluctant for them to end: an indication that this was a valuable opportunity to unburden herself to a (female) stranger.

### **Summary: Representative Lives?**

Four very different lives were described in this chapter. As commentators on their lives all gave more than adequate accounts, and other than the minor discrepancies I found in Alanna's account, the little documentary evidence I found by chance tends to corroborate their versions of events, though no one spoke of being certified. The

auto/biographies are in the methodological tradition of the open ended life stories described in Chapter 3. People do not describe their lives primarily in terms of being people with learning difficulties. As Bogdan and Taylor (1976) and Atkinson and Williams (1990) found, common human concerns with relationships, families, personal transitions were what people focused on.

The question of representativeness was raised in introducing the chapter. The auto/biographies indicate that changing practices and beliefs have framed peoples' lives, but that personal factors have a major contribution too. Each was exceptional in some way. Beryl remained in her own home after her mother's death, although documentary evidence suggests that this was unusual at the time. Bert's crimes were excessively penalised, probably because he was unlucky enough to lose his mother. Lynne had a paid job; and Alanna bore and kept her son. Yet factors which construct a continuing state of dependence are identifiable, and are linked to the learning difficulties label. They include either prolonged reliance on family, and confinement within it, or, in its absence, dependence on services; an absence of stable sexual partnerships; and a presumption of continuing dependence on others. Occupying a socially valued adult role - mother or employee - did not fully compensate, nor did Alanna's control of her own income. Nor does there appear to be much correlation with ability or social competence. Bert was one of the most articulate interviewees, but had less autonomy than most. Although practice has changed over time, factors which construct dependency appear to operate for all four age groups represented here.

Thus these four life stories demonstrate from a subjective point of view some of the themes described in foregoing chapters. They also show the importance of the biographical method for illuminating and challenging the historical record found in written sources. If the history of learning disability is to be more than the history of institutional and administrative practices, the type of oral historical approach

experimented with here will be a significant methodological tool.

The four auto/biographies indicate the extent to which gender interacts with the label of learning difficulties to create distinctive experiences. There were pressures on people to adopt conventional male and female roles, yet at the same time opportunities to perform those roles in a socially valued context were absent. Whilst Lynne was coerced into occupying a stereotypically female caring role which she resented, Beryl and Alanna apparently welcomed opportunities to care for friends and son respectively. Bert's life was objectively speaking more limited than the women's lives, and he had few opportunities to occupy conventional gender roles; but in his narrative he made the most of those he could find - hospital jobs, his various pre-hospital exploits, boxing, and courting nurses.

Personal identity was not expressed in terms of dependency. None of these respondents described themselves as dependent other than in very specific areas, particularly reading and writing. All three women have had quite significant roles as caregivers, and these were if anything more significant than their status as dependants in their accounts. Bert's account was not framed in terms of either care or dependency. Instead he seemed more than willing to embrace a criminal identity, one that apparently had more attractions than the alternative of a man with learning difficulties.

There was an absence of any sense of collective oppression. No one articulated resistance except in personalised terms. Lynne's frustrations were directed at her father and social worker personally, Alanna's at her mother, and Bert blamed other patients for the inconveniences of his life. This appears to be associated with the lack of articulated consciousness of being labelled as people with learning difficulties. As Patricia Hill Collins pointed out in relation to Black people: 'Groups unequal in power are correspondingly unequal in their ability to make their standpoint known to themselves and others' (1990:27). This observation is equally

relevant to people with learning difficulties whose history is hidden from them, and from others.

The strong contrasts between externally imposed social identity and peoples' own expression of personal identity emerging from these auto/biographies recur in most of the interview data. In Chapters 8 and 9 they are explored in more depth by reference to data from the whole group.

## **Chapter 8: Care and Caring: Descriptions and meanings**

### **Introduction**

In this chapter I describe how people talked about care and caring in the interviews. Chapters 6 and 7 show that people ground care and dependency issues within relationships, rather than as abstractions, in line with Qureshi and Walker's definition of care as 'a social relationship as well as a physical task' (1989:6, see chapter 2). This Chapter builds on this analysis with reference to data from the whole group of interviewees.

The meanings of 'care' and 'caring' are disputed in the literature (see Chapter 2). Key characteristics are care as love/affection (Graham 1983), care as labour/tending (Parker 1981), as tasks (Parker and Lawton 1994) and in some definitions (Waerness 1984), as help. Here I ground the concepts of care and caring in the language used by interviewees. No one used the terms 'care' and 'caring' spontaneously. Instead, the terms 'looking after' and 'helping' emerged as the most frequent ways of characterising the nature of care within relationships.

In order to clarify what people understood by 'care', 'looking after' and 'helping' I devote a short section to this, before exploring how relationships were described.

### **Care, looking after and helping**

An important finding is that no interviewees spontaneously used the terms 'care' and 'caring' in the way they have been conceptualised in the literature (see Chapter 2). No one actually described themselves as a 'carer', nor as a person 'cared for', or indeed 'cared about', despite the prevalence of the term 'care' as a descriptor of the services people use, for example ATC provision is generically termed 'day care' in local policy documents (Beds JCC 1988). As Morris (1993a) found 'care' and 'caring' are jargon words used by academics and by providers of services, and not terms used readily by carers or dependants.

As a way of clarifying the meanings of the terms 'looking after' and 'helping' after the pilot interviews showed these being used frequently, I held a discussion at the ATC with Beryl, Eileen, Jane, Anna and two other female Day Centre members who joined us uninvited. I set it up quite informally on a visit there with the aim of finding out what was understood by these terms, and by 'caring'.

Asking what 'caring' meant elicited 'being kind', 'cuddling', 'smiling', 'making a cake', 'giving presents', 'phoning', all words and phrases indicating that 'caring' equals expressions of affection. I then asked the group to tell me first who looked after them. The answers were 'dad' (twice), 'mum', 'sister', 'myself' (three times), 'friend'. I then asked who they looked after. The answers were 'Dad', 'staff', 'mum', three named female friends, 'Fluffy' (cat), 'Joey' (budgie) (twice). The answers are interesting in that both family and friends appear in both groups, while staff appear only as 'looked after', in the same category as pets! I then asked what you do when looking after - 'doing the shopping', 'housework', 'cooking', 'feeding', 'keeping clean' - all of which fall into Parker's 'tending' activities (1981), and Parker and Lawton's list of care tasks (1994 - see Chapter 2). Finally I asked about 'helping'. This included 'helping special care people', 'raising money', 'doing things together' and 'making coffee' (in the Centre coffee bar where we were at the time). This suggests that the group members had a fairly clear distinction in their minds between 'looking after' and 'helping'. 'Looking after' meant tasks done for intimates, family and friends, whilst 'helping' is more in the public sphere, with people who are less intimate.

This group discussion served an important function in generating concepts to use in analysis of the data. It delineated three areas of interpersonal relationships which have some resonance with academic definitions of care: caring as expression of affection; looking after as labour within intimate relationships between family, friends, pets and sometimes staff; and helping as activities in a more public and less



intimate context. These categories offered a way of structuring the chapter which was grounded in the language used by interviewees. However, they do not encompass peoples' more negative views of caring relationships, and these are discussed separately.

### **Care and caring within relationships**

This analysis is organised according to the three sets of relationships set out in Chapter 6 - family, friends, staff. I examine these relationships in turn and use as far as possible the three areas outlined above; care as affection, looking after and helping. These implicitly exclude negative and pathological dimensions, such as absence of care, or control exercised under the guise of care. In this sense they reflect much of the feminist literature on caring analysed in Chapter 2 which has similarly failed to acknowledge that care may be experienced negatively by care recipients. These more negative dimensions of care relationships are discussed separately.

#### *Caring within the Family*

Families were a uniquely important set of relationships for all of the interviewees, even those, like Beryl, Anna and Arthur, who had no substantial contact with relatives. The significance of the family, or its absence, is a topic where the interviewees' personal experiences seemed to be at one with the findings from Chapters 2 and 5, both of which suggest that policy has been to encourage families to 'care' for as long as possible, and that service interventions are intended either to bolster family care, or, where necessary, replace it.

This is shown by a brief overview of the group's biographies which demonstrates the continuing importance of families as sites for care in the lives of people with learning difficulties well into adulthood, confirming the literature surveyed in Chapter 2 Section 3. Of the 22 interviewees (median and average age at interview

43) only the four mothers established themselves in their own households in their early twenties. Nine people remained with their families until the second surviving parent died (this includes the four people still living with parents). Of the others, two (Gary and Malcolm) left home to go into residential care in hospital in early adulthood and subsequently spent several years with one parent; six (Mike, David, Janette, Isobel, Jane, Bert) went into residential care in adolescence or early adulthood whilst there were still family ties; and Anna went into residential care apparently because the family failed to provide care. Setting up their own households as young adults was the exception rather than the norm.

Using the three concepts of care as affection, 'looking after' and 'helping' I examine what the respondents said about their relationships within families.

### **Care as affection**

As far as perceptions of family care go, the data suggests that distance lends enchantment. Very few of the people living with or near parents mentioned affection as a dimension of the relationships. They dwelt upon the negative aspects and irritations of parental care (see below). Overt expressions of affection were mostly confined to parents who are now dead:

*Eileen: Oh yes 24 years ago. I came here (ATC) in September I think it was and in December she just died. She had cancer. I was only 16. I still miss her.*

*Arthur: You lose your best friend when your dad dies.*

*Bert: I liked me mum though, she was good to me she was .. yeah when she died I was bad for a week, collapsed with shock you know.*

*Sheila: They said to me parents I'd never be able to drive, things like that see, people wrote me off, thought I couldn't get on in the world but I have ..think it was the encouragement of me parents really.*

*They wanted me to get on and I just got on.*

In some cases loss of a parent created real trauma. Arthur was not specific, but I suspect his dad had protected him, finding him work they could do together, bricklaying. Arthur subsequently lived in four different mental handicap hospitals until he came to live in a group home in Luton in 1990. We know that Bert's loss of his mother entailed his continued residence in hospital, and that Beryl temporarily lost her home when her mum died.

Physical distance also made families seem desirable. Both Gary and Janette have parents who regularly take them home on weekend visits. Both spoke of their parents with affection. It is perhaps easier for people living away from immediate contact to recognise the positive aspects of a family's care, especially when efforts are made to keep in touch and include people, as Gary's family did.

Current sibling relationships were often described as affectionate and companionable. This was particularly characteristic of male respondents, though these were also people living at a distance. Malcolm, Bert and Mike all presented their brothers as companions and friends on a relatively equal footing. Malcolm put it neatly:

*Over the Bank Holiday me brother came down. We went to the carnival. Me brother pick 15 pounds up. Walk a bit further I pick 15 pounds up.*

Bert looked forward to working with his brother as a plumber and Mike reminisced about his brother:

*My brother's handy with guns, takes 'em apart, makes sure they're working, then puts the bullets in .. I fired one, I fired me brother's, but it's difficult to shoot straight.*

This differs from the ways women describe their sibling relationships which are

more readily characterised as looking after, or as Beryl put it, 'keeping an eye on' (see below). However, the companionable relationships with brothers described here are also at a distance and thus in line with the findings about relationships with parents.

People who did not have families usually wanted them. As Beryl's account in Chapter 7 shows, absence of family was a matter of regret. People found reasons for such absences. Bert (Chapter 7) cited the cost of transport. Mike (Chapter 6) mentioned pressure of work. Expressions of affection within family relationships were mainly expressed when families were either lost or at a distance.

### *Looking after*

Descriptions of day to day family relationships focused much more on practical tasks than on emotions, and the term 'looking after' was frequently used. Looking after was a two way thing in the eyes of those 12 respondents who lived with or near families. Indeed, the emphasis was as much on tasks done for parents than on what parents did for them.

For the younger women in the sample, those under 40, parental interventions were seen as a mixed blessing. This was complicated by the presence of a child. Stella's memories echoed Alanna's experiences of conflict with her own mother over her role as mother suggesting that the three generation family was full of tensions. Stella lived alone, but had frequent contact with her mother. Much of the interview focused on her pride in having a daughter, now being fostered, and her mother's role in relation to her grand child. Here she describes her pride in looking after her daughter:

*My first child and I look after her, I was glad to have her and everything. I feel let down really (at losing her) cos they could have exchanged the flat. Cos I was washing her hair and plaiting and*

*oiling it and her skin is dry now. Cooking for her you know, like baked potatoes, rice, minced beef. I did all that for her.*

Reflecting on her mother's interventions, she recalled principally the conflicts:

*I don't get on with my mum at all, well she trying to look after my daughter, didn't get on with her when she. I never wanted that. I'm at home and I can look after her .. she's trying to look after my daughter, didn't get on with her at all.*

Stella's frustration with her mother continued:

*I want to do it meself but she wanted to help decorate this flat.*

Yet she also recognised, and implicitly sought, her mother's help:

*She got my social security book, I gave it to her to save up to get me a fridge and freezer and a cooker.*

Stella was reluctant to acknowledge that she needed looking after by her mother, preferring to emphasise her role as a carer, albeit frustrated by the loss of her child.

Jane also lived independently, with her father nearby. Initially she gave me the impression that the relationship was harmonious, even reciprocal, but Beryl's arrival in the interview prompted a different story:

*Jane: Me brother keeps me in order doesn't he?*

*Jan: Why do you need keeping in order? ..*

*Jane: Why do I need keeping in order Beryl?*

*Beryl: Your dad hasn't got patience with you .. well she play up now and again, play he up don't you? .. when he come round she start to play he up, he told her before he went (to Australia) if she play up one of these days he stay over there, if it weren't for the grandchildren he stay over there*

*Jane: Yeah I say to him why don't you go and live out there, he say  
if it wasn't for the grandchildren I would*

This was followed by revelation of Jane's past. She went into hospital after her mother died, because her father couldn't handle her 'playing up' - or that is what she thought. Though little actual 'looking after' was involved, there were apparently tensions over Jane's autonomy and adult status in the eyes of the family.

As parents grew older the dynamics changed. Three people still living at home - Eileen, Barry and Lynne - had taken on some household tasks for parents as they aged. Three women, Beryl, Deirdre and Denise, remembered looking after older parents before their death. This was invariably expressed as doing housework, shopping, cleaning, washing: in other words 'tending' (Parker 1981), including some of the tasks described by Parker and Lawton (1994), though no one mentioned performing personal services, such as washing or dressing.

The meanings people attributed to these responsibilities varied. They can be grouped into two. The first group regarded caring for parents as a burden. Lynne said she was looking forward to living independently 'before I get really old'. Her sentiments were echoed by Denise, who had lived with her increasingly demanding mother until her death:

*Well I wasn't allowed to go out on me own and leave her actually in  
the house on her own, she was a tyrant .. she made my life a misery  
you know.*

In both Lynne and Denise's accounts parental care, and caring for parents, were unwelcome. The demands made, for companionship and for household duties, were resented as a restriction on freedom. Both women emphasised the control parents continued to exercise, even when they were ill and reliant on the care of others. Denise had been freed of those responsibilities: 'I can go anywhere now, do what I

like'.

Other interviewees spoke of status and satisfaction from looking after their parent. The burdens of being a carer were not emphasised. This group consists of Beryl (see Chapter 7), Deirdre, Barry and Eileen. Like Lynne and Denise the caring they described comprised shopping, washing, cleaning, preparing meals, and in Barry's case gardening. Eileen described what she did:

*Yeah we cope very well actually. I do the shopping for him and the washing up. I do me own washing.*

Later she modified this account:

*He comes with me (shopping). I say to him "what would you like from the shop, I'll get it for you", and he says he doesn't know what he wants to put down in the letter so he comes with me, Saturday afternoons.*

Growing infirmity was pushing more responsibility on Eileen. At the time of the first interview her father was still cooking, but by the time we last met, four months later, Eileen was doing this too. Eileen's account was positive, but there were signs that this was for public consumption. She suffered from depression, and was hospitalised for it some months after our interviews. Her father still controlled her income, and exercised restraints on her behaviour, for example:

*My dad don't like me reading out loud. I have to read quietly cos he can hear me. You're not supposed to read out loud are you really?*

What characterised the three women who were positive about their caring duties was a pride in having something to offer the parent they care(d) for, something that was absent from Lynne and Denise's descriptions. Eileen again:

*I think my dad needs me. I leave him for a weekend. I've got to leave him for a week soon. Hope he manages all right. He's lovely, my*

*dad.*

As parents aged the balance of dependency changed. This was not the case with sibling relationships. It was unusual for people to see themselves as caregivers in relation to siblings. Stella recalled giving care to her brothers and sisters, something which she regarded as having given her valuable experience when she had a child of her own:

*I knew how to look after her (daughter), because when my brother was a baby and mum and dad went out to work I used to look after them and grow them up, I'm the oldest one .. I knew how to change them, clean them, I didn't need any help.*

This was cited as evidence of the injustice of her child's being taken from her care. She was technically competent to look after children - so why not her own?

These findings, that individuals who care for family members, interpret and experience it in a variety of ways, are in line with other research into caring within the family (for example Lewis and Meredith 1988). What is distinctive, though, is that women with learning difficulties who undertake these 'looking after' tasks remained dependants in the eyes of parents. Their biological adulthood was not fully acknowledged socially, especially in terms of managing money, and in Stella's case, caring for her child. There was only one man in the group who lived at home. He presented looking after his mother as his choice, and he did not dwell on the restrictions.

For people still living at home, the death of the second parent represented a key transition point. Beryl, Malcolm, Deirdre and Denise all singled it out as a time of significance, and both Barry and Eileen anticipated it bringing in its wake major changes. For Eileen it may have entailed moving to her sister's; Barry described it as an opportunity to marry Isobel. This event is often represented in the literature as



a double loss, loss of parent and loss of home. However, this was not invariably the case. For some it represented a new freedom. Both Malcolm and Denise saw it like this. Malcolm went into hospital when his family split up when he was about 20. Later, when his father remarried, he came to live with his father and step mother in Luton:

*Jan: What about your dad? Did he look after you?*

*Malcolm: He used to see to bills. That's all he were doing, cooking and bills.*

[In 1983 his father died.]

*Jan: So you had to look after yourself suddenly.*

*Malcolm: All of a sudden. Had a bit of help.*

*Jan: Who helped you?*

*Malcolm: Social workers. Had a bit of help from Church Street .. I didn't have no training. They've had training but I hadn't. Odd isn't it .. certain things I still can't do, like a joint of meat, I can't do it properly.*

His father's death represented a transition point, enabling Malcolm to develop his own self care skills, which, in his own eyes, he had accomplished quite successfully and with minimal help from outside. For others, like Deirdre and Bert it entailed real loss - of home, neighbours and community.

The role of siblings as potential givers of care assumed greater importance after the death of parents. Eileen's sister already attended her reviews at the Centre, and Eileen expected to live with her after her father dies, 'if anything happens to him' as she put it. She looked forward to 'helping' her sister, but not to the easy companionship described by the men. She intimated that living with her sister was

not her choice, but appeared not to be able to say this for fear of being impolite.

Other people had expectations that brothers and sisters would look after or help them. Bert expected his brother Don to offer him a job when he left hospital. Malcolm's dearest wish was to move north to be near his brothers and sisters. David said 'I'm sure I can go to my brothers but his house isn't big enough'.

Yet past arrangements to live with siblings had all been fairly short term. Beryl's sister in law could not accept her, as she put it. Deirdre moved in with her sister briefly after her mother died, but this did not last, and she went into a hostel in a nearby town. Both Bert and David had come out of hospital and spent some time living with their brothers. The reasons for these living arrangements ending was not made explicit - both men were back in the Hospital. Lynne's sister lived at a distance, and had little contact with Lynne. The only intervention mentioned was a rebuke: 'Me dad's not allowed to stop me going out .. cos me sister told him off once before.'

The evidence is patchy, but it appears that whilst many siblings were ready to offer help, they were inclined to offer that help at arm's length, rather than take on 'looking after' at close quarters. It remained to be seen whether Eileen's experience would be any different.

### **The uncaring family**

There were people who found families uncaring. Though presumably fairly common in peoples' experiences of family care, abuse, neglect and rejection were rarely dwelt upon. It is hard to imagine, for example, that Isobel did not feel rejected when at 13 she was sent to hospital which she hated, but at no time did she refer to this. I would not imagine it represented the 'truth'. Rather it reflected the interview situation where we mostly obeyed the rules of polite conversation between relative strangers. These are not easy feelings to acknowledge in such

interchanges.

Alison was the exception to the rule of reticence about family neglect or cruelty. She declined to have the interviews tape recorded, and instead wrote her own 'story':

*I was born in Hackney and we moved to Luton when I was 10 days old. My dad abused me at the age of five right up until I got married first time round. Then he tried to abuse my daughter who was only two at the time.*

She married, she wrote, because:

*I wanted a place of me own away from me parents. My dad because of the abuse, and my mum because she used to knock me about.*

When she took a drug overdose 'me mum was the last to know'. I suspected Alison's frankness was possible because she took the option of writing her own account, and it may have been due to a greater sophistication than many of the interviewees, perhaps resulting from working with counsellors, and her practice of expressing her feelings on paper.

Most confidences about feeling rejected or neglected were imparted subtly. David, for example, said 'other people go home (*from hospital*) and I don't you see. It's not right.' This was especially poignant because his sister, also with learning difficulties, lived at home. Favour to a sibling was something Sheila mentioned: 'She always looked after me sister more than me, me sister was always there .. I sort of felt pushed out at times .. I'd have liked a bit more'.

People found reasons for families' apparent neglect. Mike, who had recently found himself in hospital after his father died, was fiercely protective of his mum, perhaps covering up a sense of confusion and rejection: 'Anything goes wrong with her I'll stick the boot in .. my mum can't come here, she works, she works till half past five

cleaning toilets, washing stuff'. Bert referred to the high cost of the rail fare when he talked of his mother's failure to visit him in Magull.

Of all the interviewees Anna had the most fragmented memories of family life:

*I used to have, er I used to have a lot of people of mine .. when my mum used to have me home Boxing Day that dog was on my lap all the afternoon, never moved.*

Anna's parents, (possibly step parents), had vanished from her life some years ago. All references to them were couched as 'used to'. She has lost touch with other family members: 'well I have got a sister and a brother, but they aren't bothering me. Move. I don't know where to'. The result of this absence of family was that Anna seemed excessively reliant on the paid care of others - they formed her network of care. As she had moved home five times, at least, since being discharged from Bromham, this suggests a certain fragility.

### *Summary*

Care within families is a complex subject. It was unusual for people to be positive about what their parents offered them whilst alive, unless they lived at a distance and remained involved. By many of those currently experiencing it family care was seen as controlling, neglectful, or burdensome, though care giving could be a source of status. People were not inclined to describe themselves as being 'looked after' by parents, though many could see their value in retrospect. Reciprocity was rarely indicated, except in men's relationships with their brothers.

What people seemed to value was being a part of a family network, and involved in its doings. Gary's brothers and sisters, for example, had fetched him to attend his mother's engagement party. Other people who mentioned family were less fortunate, and, like Beryl, dissatisfied about the level of contact. Malcolm, for example; 'me step mum can be a bit funny, you know what I mean? .. She (*step*

*sister*)'s stuck up. She's got a bungalow, she's got everything'.

There was an interesting gender dimension in attitudes to family care. Women were much more inclined than men to describe their relationships in terms of tending activities, and to emphasise their competence as carers. There were also more obvious tensions in women's family relationships, frequently centring around the right to be treated as an adult, to move around freely, and to control their own incomes. Being a carer, whether for a child or an ageing parent, often exacerbated these tensions.

### **Friendships**

Caring within friendships was important to most people and unlike family relationships, friendships were apparently motivated by affection. Reciprocity within friendships was far more common than in family relationships. This was particularly noticeable with women. Denise and Deirdre each lived with one other woman and both used shared household tasks to symbolise the give and take of their relationships. Deirdre described it like this:

*You know we go shopping, my friend and I, we just walk out the flat and we're in the shopping centre .. we both do that usually, cleaning all the bits and pieces up, dustin', washing, everything.*

Denise and Gloria shared confidences about their boyfriends, and their aspirations to marriage. They went out on dates as a foursome.

Doing things together was an indicator of reciprocity. Eileen, Beryl and Jane had holidayed together, and been on trips. Kay and Deirdre also holidayed together, and visited the market. Alanna conceptualised friendship as having someone to do things with - in the absence of friends she shopped with her mother, and used to go to pubs with her brother.

Sharing was characteristic of Malcolm's view of relationships; at the Speaking Out

Group at Church Street he met friends . He said they talked about:

*Different things like telephone boxes what's been damaged, bus shelters, names what we've been called*

Malcolm introduced his friendship with Andrew as one of give and take:

*I help him and he helps me .. he comes up here and I go down there.*

This fitted well with Malcolm's approach to life. As he said, 'If anyone wants to look after me I'll look after them'. But Malcolm also derived status from being a helper in a more public sphere:

*At the moment Andrew's run into a bit of trouble with his brother. And his brother's been over to me to help out. Social workers moved him to a hostel without his consent. And I'm more or less helping out .. I've been to social workers and that. We're going together. I've seen everything happen. And I can help out.*

Malcolm's quiet confidence in what might be called an advocacy role singled him out from the other respondents, male and female. Whatever the rights and wrongs of his intervention, he clearly saw himself as having the personal resources to do more than offer simple domestic help, or companionship, to Andrew.

The idea of 'helping' was used in the context of friendships. It may have been that the subject of the research, 'caring' produced data implying that friendship meant doing things for someone as well as with them. Most people were best able to verbalise friendship as their ability to do things for others, or to have others to call on to do things for them. Jane and Eileen both drew attention to what Beryl did for them - she made Eileen's birthday cake, and cooked all Jane's evening meals.

Several people described friendships with people who were in some way 'dependent', for example Gordon's friend Carl was in a wheelchair and Gordon remembered how he'd wheeled him to the toilet whilst they were both in hospital.

Janette responded to my question about friendship by mentioning helping her friend Pat who is in a wheelchair, as did Anna whose friend Hazel was physically disabled. In these cases being a friend included having someone to depend on you, even if it was only for minor favours such as being taken to the toilet. We may speculate, however, that with a limited vocabulary concrete helping was the easiest way for people to describe friendship.

Within heterosexual relationships, care was most often expressed as practical help and support, frequently singling out men as the givers. Barry told me how his presence at Isobel's interview gave her confidence. Gary described what he did for Sue:

*She's not very steady on her feet .. I take her hot chocolate every night in bed. She likes her hot chocolate. I look after her in many ways. Do her shopping at weekends what she wants.*

From the woman's point of view, Lynne also emphasised how Eddie helped her with the shopping, and made sure she had enough to eat. Affection was indirectly expressed through these practical means, and Isobel and Barry made it clear that their relationship was sexual too.

Elements of friendship then included:

companionship - sharing the housework, going around together

helping - doing things for others, being needed by someone else

receiving - having someone to do things for you

This was the positive side. On the negative side, some interviewees seemed to use their friends to give themselves status at the expense of the other. Being a helper was a source of status, and may have brought with it the exercise of power. I felt that Beryl gave herself status by helping Jane and Eileen, but in some respects at the expense of their autonomy. For example, when Eileen responded with

enthusiasm to a question about work with children, Beryl quickly squashed the idea:

*Make er childish being with children. She lose 'er pension if she go out to work. She do what she's told, always say yes don't you?*

She capped it by telling Eileen her father needed her. Beryl's quasi-parental role in relation to her (much younger) friends shaded into 'looking after' with its attendant tensions and asymmetry, and may have been based on role models in families or amongst staff. In this she demonstrated that being a carer or someone who 'looks after' others is a source of both status and power vis a vis the person on the receiving end.

### **Service providers**

Most people had contact with service providers on a regular basis over time. The three categories of affection, looking after and helping do apply equally here as to family and friends, though do not readily lend themselves to the more negative reflections on relationships with staff.

#### *Affection*

Service providers were often regarded with affection, and elements of reciprocity characterise these relationships.

Both Alanna and Alison regarded their social workers as friends and supporters. Alanna relied on her social worker as a confidante. At the same time her son's social worker provided practical help and advice on bringing John up. Alanna was aware that she also owed her social worker the obligations of a friend 'she's somebody I can tell everything to, she'll keep it to herself .. I hope it doesn't bring her down too much. She's had a bad time of it herself this year, poor thing'.

Alison was firm in rejecting any notion that her children were removed against her will. She wrote:



*You asked me how I felt about my children going to live with new parents. It was not a decision I made lightly. It was very difficult. I worked with the social workers, and not against them. I did it this way because my eldest trusted the social worker.*

In a lighter vein, Eileen described the workers at the ATC as pals. Her key worker, Carol, was mentioned when she took a second biscuit, contrary to her diet:

*I'll get Carol to sort me out .. no she's not fierce, sort me out .. she's lovely, I get on with Carol .. Mr. B, he really is great. He's a torment, I'll tell you that much.*

This type of easy relationship was also implied by Barry who hinted at collegiality with the professionals on the User Forum he attends - 'VB, all that lot'. He used some phrases reminiscent of professionals' language, such as 'Sort of challenging behaviour, sort of thing'; 'Some might be self inflicted, sort of'.

This category also includes Bert's romantic attachments to nurses (see Chapter 7), an attitude shared by Mike; 'I fall for the prettiest ones with the nice figures, not for all of them but the nicest ones'.

The best relationships with staff seem to be characterised by affection, reciprocity, and a notion of working with rather than for or at the behest of workers.

### *Looking after*

The only interviewees who were explicit that they needed looking after by staff were Anna and Gary, both of whom live in staffed accommodation. Anna told me:

*See when they go out at night if I don't want to go out someone there to look after me.*

Anna's living situation meant she was unable to invite me to her home. That had to be done through Mary, the home owner.

Gary believed that his fits put him in danger, and that was why he needed staff:

*I can't bath myself, if I have a bath there's always someone there to look after me.*

The protection extends, with Gary's tacit consent, to his communications with others. He would not agree to see me for a second interview until he had checked with staff, and the results of a medical test he'd had 'would come through staff, not me'.

The two men living in a staffed group home, Arthur and Gordon, did not speak of being looked after by the female staff, though I observed that they were in practice being served by those staff. One care worker had knitted Gordon a pullover and gave it to him whilst I was present, and there was no question that staff made the tea. I speculate that these men had long experience of being looked after by women staff, from hospital days as well as in the group home, and took it for granted in a way that the women did not.

### *Helping*

Helping relationships with staff were more commonly described. Mike, for example, emphasised his role as a helper in the hospital:

*Helping the staff keep order, keeping the lads and lasses under control .. one of the staff is away, they chose me to help out.*

Referring to an incident in which Sister hurt her hand he said 'Yeah well she needed our help, if we'd a been around to help out that would never have happened'. Bert's hospital job with the porters can also be seen as helping.

Whilst Mike represented himself as helping keep order, women claimed for themselves more nurturing roles. Denise sat with less able residents in the group home next door, 'Helping out when they are short staffed'. Eileen and Beryl recalled when they had been called upon to assist in the ATC. Eileen became quite

animated when telling this anecdote:

*Oh guess what I did it were lovely, I walked one of the special care ones over to special care, they were short staffed or something, I said "oh come on, I'll do it". I loved doing that.*

In hospital Anna had helped by looking after children, giving them breakfast and dressing them.

In some cases, helping was not voluntary but coercive. Isobel had had to look after the doctor's children whilst in hospital:

*One day I looked after the doctor's children, Dr. Smith's children at Bromham. I used to work there. Little children. I give 'em bread and jam .. didn't get paid for it, no, didn't want to do it.*

The eagerness with which some of the women seemed to grasp helping roles in which they cared for others contrasts with the jobs men claimed, activities like keeping order or portering which are more consonant with masculinity. But for both men and women being a helper to staff was usually regarded positively. It may be significant that these were roles they had chosen.

Receiving help from, as opposed to being looked after by staff, was readily acknowledged. Several interviewees singled out particular types of help they'd received. Sheila was adamant that her special boarding school 'was the best thing they ever done for me' because it taught her to overcome her speech problem. Such was her confidence that she was trying to get her eight year old son into a similar school:

*Me youngest boy's got the same as me .. he may get over it like I did.*

Others, like Beryl and Jane, mentioned being taught specific skills, such as cooking; and Beryl recognised she needed help in writing cheques. Even Malcolm, keen to stress his independence, was ready to acknowledge 'had a bit of help from Church

Street', though he emphasised this was on his own terms: 'If I need help I know where to ask'.

In this helping category fit most relationships with home helps/care assistants. Perhaps because they have a defined role, to offer support in the home, they were for the most part regarded as simply helpers. Malcolm, for example, had a home help, but this did not diminish his sense of being able to look after himself. Jane had a home help who supported her in cleaning her flat. Denise's family aide came on Wednesdays 'she gives me the money so I don't buy too much'. Being in receipt of support from domestic helpers was perhaps more acceptable as they are not exclusive to people with learning difficulties and carry fewer overtones of dependency or stigma.

Not everyone felt they were getting the help they needed. Denise commented 'But, um, I haven't seen my social worker for some time I'd like a little chat with him sometimes you know. He says I can ring up any time.'

Deirdre was concerned that promises made to her had not been kept:

*Well, they said I might get a job, escort on the mini bus you know, I haven't heard anything about it .. I don't do nothing, only the housework and washing and that.*

Jane also felt she had been abandoned by her social worker. She had not turned up to her Review at the Centre, though she was expected, and had not been in contact since.

These three people lived independently. It is perhaps worth noting that although they appeared to be managing, the wish for regular and reliable contact was still present.

### *Uncaring relationships*

It was unusual for people to overtly criticise staff with whom they were in current

contact. Other than Lynne (see Chapter 7) only Stella was outspoken in her criticism. She emphasised her sense of powerlessness:

*No one ever explained to me why they took her (daughter) away, they say no I can't have her back at all, I don't know why.*

In discussing her treatment in hospital, for schizophrenia, she said:

*Treat me bad up there, they treat me very bad up there, they rough me up a bit you know for no reason they think I'm stupid, they think I'm really stupid, you know, push me around.*

Lynne's experiences with her social worker and home cares (see Chapter 7) had some similarities with Stella's experiences. Both indicate disregard for their interests; in Stella's case presumably her daughter's interests were put before hers. In Lynne's, her father's needs were paramount.

Ill treatment in the past was perhaps a safer topic. This was told through stories, apparently well rehearsed. Two people who had experienced hospital care recalled some of its more negative aspects. Bert's description of 'booting' has already been quoted in Chapter 7. Isobel's account of her stay in hospital was vivid and angry:

*I got locked in. I had lovely hair right down the back. And they cut it .. they tie me in the chair. I refuse. Tied me in the chair cos I didn't want my hair cut. They cut it all short .. by scissors. Cos they didn't want long hairs in hospitals. It was like that. Then after that got punished. They put me in a dark room on a mattress. Quarter/half hour, and then they took me out and injected me. Yeah. Long while ago.*

Isobel also described successful resistance to cruelty:

*She (Sister)'s terrible. One day I went in the canteen long while ago, stopped all the money, told me brother, he told Dr. Fleming (the*

*Medical Superintendent), he rang up and Dr. Fleming told me, he said 'don't worry about it Isobel, don't worry about it' he said. So I got me money back and she got the sack.*

Gary used a similar metaphor to describe punishment at his boarding school when he spoke of being tied in his sleeping bag, and resistance in the form of cheeking teachers.

### *Summary*

It emerges from this analysis that people valued relationships with staff which permitted a degree of reciprocity, whether in emotional terms, in engaging in a shared task or in being able to offer something in return as a helper. Being a person who is looked after, as opposed to being helped with specific tasks, was something which few people identified with. This is consonant with Simon's research. He writes 'it is also clear that self advocates want to work with staff, preferably on an equal basis' (1992:74).

Lack of care, abuse, or neglect were aspects of relationships with staff which were rarely mentioned, and often only if they were safely in the past. These were overall the subject of silences. My perceptions were that some people were neglected, even open to abuse. People living with families who appeared to be jogging along had no one actively helping them look at options or alternatives. Eileen had been at the ATC for 25 years and had no prospects of change. Evidence of neglect was that Eileen had been ill and had a tumour removed when it was weighing 12lbs. It had not been noticed or treated until it became critical. When I visited Anna's home for tea I felt that there was too little to eat - it was unclear what residents there could do if they were going hungry. That these insights were from my own observations, not from interview data, indicates a limitation of the method of focusing exclusively on the interviewees' verbal accounts, and the importance of looking for what is not said, as well as what is.

From a gender perspective a number of the women singled out traditional female caring roles as 'helping', whilst men chose to emphasise activities which require physical strength or public negotiating skills, like Barry. Equally, some men appeared to accept being 'looked after' as a taken for granted part of life, whilst of the women only Anna was willing to describe herself as in need of being 'looked after'. Women to women relationships with female staff could be characterised as friendships. For men in residential care, there was apparently no such choice. Instead, they polarised. Some accepted being looked after by female staff, others struck a chivalrous or flirtatious pose, the latter being the option chosen by Mike and Bert.

### **Other Relationships**

It is an indication of the very segregated nature of most peoples' lives that relatively few people mentioned relationships which do not fall into the categories of family, friends or staff (other than relationships with other service users in ATCs, group homes and hospitals).

In general, such relationships were related to paid or unpaid work outside the home or service setting, to membership of a community facility, and to the community contacts fostered in particular by Malcolm and Lynne.

All of these relationships constituted 'help' as opposed to 'care' or looking after, which is consonant with the definition of help as activities undertaken in less intimate relationships. Help was given within two main contexts: formal voluntary work arrangements; and other community activities.

### *Voluntary Work*

Several interviewees were engaged in voluntary work. Jane worked in a play group:

*Just Wednesday mornings at the moment, help look after the children and play with them and that, do jigsaws with them and that,*

*we make things with them, like they do painting and that garden.*

By our third meeting she had taken on a new set of tasks, working in a play group 'for children with learning disabilities' as she put it.

Arthur helped at a Centre for homeless men, five days a week. He swept the yard, did vegetables, and washed up. He regarded this as an important job for which he might well be paid:

*Don't know what they'd do without me down there.*

People were obviously proud of being volunteers, even though the work was unpaid and relatively humble in status. It was an indicator that they had something to give, though the staff at the Homeless Centre where Arthur worked saw him as another client, albeit in a different category to the homeless men (personal observation).

#### *Community contacts*

Malcolm created his own niche in society by becoming a helper:

*It's these people can't walk, who can't get out of wheelchairs, I used to take 'em out, to shops where they wanted to go. If they couldn't get out to the shops I used to go in for 'em. If they couldn't get out the house they used to write a list out, I used to go down for 'em.*

Malcolm had given this up. As he said 'with me wanting to move you can't do much, can you?'. Instead he'd taken on the job of helping his friend's brother and their family in negotiating with social workers.

These two activities fitted Malcolm's philosophy 'that's how we can help each other.' There was no expectation that he would get something back, though occasionally he did:

*If I got a letter I couldn't understand it they used to explain it to me.  
I thought to meself I'll pay back .. but I didn't ask for no favours*



*back.*

When asked why he'd looked for helping opportunities the answer was simply 'Gives me summat to do. Keeps me busy.'

Malcolm was active in the self advocacy movement, having been to a National Conference run by People First in London. It seemed to have given him confidence in tackling social workers over his friend's brother. He related to me as an equal. Of the Conference he said 'Did I see you there? I thought you might have been a member of it. I though you might have your own little group.'

Barry was also a member of the local Self Advocacy group. This gave him a public role:

*User Forum, I go once a month on Mondays .. well we discuss moving out (of hospital) .. There are some people moving out, sort of challenging behaviour sort of thing .. I think they (neighbours) feel a bit better about it now. VB's seen 'em.*

The only woman to claim a public community role was Lynne through her membership of the Salvation Army where she helped out by selling newspapers.

Examples of people being helped by people in the community other than friends, family and dedicated service providers were rare indeed. I found only one concrete example; Lynne said 'if I want a prescription I pop into the Library to do it for me'. She also mentioned friendly relationships with the estate agents where she used to draw her wages.

Whilst it is not possible to be sure, as people may have omitted to mention other sources of help, it seems that 'the community' at large furnished little support.

## **Conclusion**

This examination of the way people described their relationships shows that they

saw themselves as more than dependants, reliant on the care of others. Even within families people struggled to sustain a sense of themselves as adults who had something to give to others, and many were able to do so. This shows that personal identities was more complex than the social identity implied by the label 'people with learning difficulties' (Atkinson and Williams 1990). Ties of affection were rarely made an explicit locus of attention. But affection was expressed through helping others, and receiving help, too. The most fraught areas were in 'looking after', both being looked after, and looking after another. This came to the fore most obviously in the context of relationships with parents. Younger women, all mothers, found themselves at odds with their own mothers over caring for their children; middle aged people, especially women, often did regard themselves in a 'carer' role, and some of their experiences echo the findings of feminist research into caring in the home - that it is burdensome, restrictive and unrewarding. This appears to be exacerbated by being a woman with learning difficulties, because parental habits of treating them as children, in areas of finance and freedom of movement particularly, seemed to persist even while the balance of dependency shifted.

Whilst instances of integration and community presence were rare - it seems that care by and with the community was in its infancy in Luton 20 years after Michael Bayley (1973) articulated this ideal - friendships with other people with learning difficulties were a very significant source of companionship and reciprocal relationships. The tendency has been for practice inspired by normalisation and integration philosophies to dismiss such relationships (Chappell 1992), but this research suggests that one positive effect of static segregated services has been to foster such friendships, a factor identified by Richardson and Ritchie (1991) and Simons (1992).

There are clear issues over social identity vis a vis personal identity, and in the

different ways gender impacts on identity. It seems that many women had internalised a sense of themselves as carers and nurturers of others, including members of their own families, friends, other service users, and staff. For some this represented a choice. Others, like Lynne, felt they had no choice. For men, the roles they took on as nurturers were more likely to be a positive choice, especially in the context of heterosexual relationships. In relationships with staff, usually female, men apparently did not exercise the option open to women of aspiring to friendship. Instead they could either be mothered, or create for themselves a quasi romantic attachment.

The final data analysis chapter, Gender, Caring and Identity, focuses explicitly on personal identity, with a particular emphasis on gender.

## **Chapter 9: Gender, Caring and Identity**

### **Introduction**

This chapter develops the discussion in Chapter 8 by looking at ways people expressed their identities. If the majority of interviewees did not describe themselves as simply dependent on the care of others, how did they view themselves? Clearly personal identity is multi-faceted. We all play numerous roles in life and, though the range of roles open to people with learning difficulties may be limited, the discussion so far has shown that people find a variety of ways of describing themselves which is at variance with the rather one dimensional picture presented in much of the research on caring (see Chapter 2). The discussion here begins by looking at how people dealt with the label(s) imposed upon them by others - how far did people acknowledge being labelled as having learning difficulties or its equivalents? I then move on to examine a contrasting role, one people claimed for themselves, that of worker. Finally, I look again at gender and heterosexual relationships, and examine how people expressed themselves as men or women.

### **Labelled People?**

This section looks at whether people identified with the label 'people with learning difficulties'. In Chapter 8 I showed that the assumption both in popular discourse and in the literature on women and caring that these are people who need the care of other people is not reflected in the way relationships were described. As Jenkins and Aull Davies (1991) put it 'self identity, while based upon an individual's interpretation of social relations, is not necessarily congruent with the public identity imposed by others.' If people did not see themselves as simply dependants, did they accept that they were known and treated as people with learning difficulties? If so, what did it mean to them? If not, were they simply trying to 'pass' as normal, as Edgerton argued (1967 - see Chapter 3), or was it more

complex than that?

Being labelled as a person with learning difficulties was not an area systematically explored in the interviews. Usually both I and the interviewee maintained a polite silence on the matter, reflecting my own discomfort with introducing a subject I felt might be awkward. (Shakespeare (1993) addresses this in discussing how interviews are constrained by the rules of polite conversation). I tried asking directly in one of the pilot interviews, with Deirdre, and this was the result:

*Jan: I mean, this place (ATC) is for people who have learning difficulties, handicapped.*

*Deirdre: Yes, that's right, yes it is.*

*Jan: You don't appear to me to have learning difficulties.*

*Deirdre: No no I don't.*

*Jan: So what brought you here in the first place?*

*Deirdre: I think my social worker suggested it.*

Subsequently I only addressed the question directly when the opportunity arose, or when it appeared pressing. Therefore the data is inferred from indirect evidence using the interview data.

The way people negotiated their labels falls into four categories: people who labelled themselves; people who denied or resisted being labelled; people who obliquely referred to labelling through reference to autobiographical experiences; and people who labelled themselves indirectly through acknowledging that they associated with disabled people. I use these four categories to structure the discussion.

#### *People who labelled themselves*

Few of the interviewees actually applied labels to themselves. I have picked out the

terms those people used about themselves - *handicapped, learning difficulties, backward and slow* - and illustrated with quotations.

Gary alone described himself as 'handicapped'. During our first interview Gary referred to an incident from 10 years earlier:

*I don't know if you saw it in the paper about the epileptic and handicapped boy who got thrown in the river.*

He was referring to himself. When I questioned him about his description of himself as 'handicapped' he answered 'Well because I have fits I still look on it.'. He had an apparently well rehearsed account:

*I was born OK and when I was 18 months old I was unconscious for 10 days and my brain didn't work properly..and when I was two and a half I started having fits.*

Gary accepted the consequences of his fits as meaning he needed looking after (see Chapter 8). He was unable, for example, to marry Sue, his girlfriend:

*Well they think because we have fits it's very difficult ..they don't think we could go out and do a proper job and earn proper money and that sort of thing.*

Although 'they' rather than he had drawn this conclusion, he appeared to concur with it.

The fits also meant he could be recognised as different, and he commented upon the problems it caused:

*I wear that hat nearly all the time. Especially the youngsters, they make a lot of fun of me, especially the coloured boys.*

In using the term 'handicapped' about himself Gary linked it specifically to a recognised medical condition, and also recognised its consequences in many areas

of his life, including the need to be looked after (Chapter 8). In drawing these conclusions Gary was uniquely aware of the impact of his condition.

Two of the mothers, Sheila and Alanna, described themselves as having 'learning difficulties'. Both related these quite specifically to difficulties in reading and writing, their own, and their children's'. In answer to my question 'I don't know whether you regard yourself as someone with learning difficulties, do you?' Sheila replied 'I was actually..I had a speech defect'. Later she said 'me eldest's got problems with learning but they are all brighter than what me and me husband are'.

Alanna said of her son John:

*He's just got a learning difficulty, he's not able to read or write, you see it's like meself when I used to go to school, I couldn't read or write.*

It is possible that Sheila and Alanna were open about their 'learning difficulties' because they had overcome some of the limitations it implies. Both had children, and were bringing them up. As Sheila said:

*They said I would never be able to stick to a job, not even learn to drive a car or anything, but I done all of it.*

Like 'learning difficulties', the term 'backward' was used in relation to problems with education, and implied dependency only in specific areas. Bert and Gary both said they used to go to a 'backward school'. Stella also used the term 'backward'. She attributed her problems with learning to her period in mental hospital and subsequent treatment:

*After taking these drugs I get very backward. When I wasn't taking any I knew how to read and write and do sums, add up, you know I knew how to do that, but since I been taking these drugs..*

Eileen mentioned that her sister had turned to a 'darkie doctor' and said to him

"She's a bit slow" - it's hard when you're slow, Jan'. She then quoted the doctor's opinion 'That darkie doctor, he said "you too good for this place. You oughta be out at work"' only to be immediately told by Beryl 'He were only joking, darlin''. However, this indicates that she recognised a link between slowness and being in 'this place'.

### *Denial and Resistance*

Just as it was relatively unusual for people to use any recognisable label about themselves which is linked to being people with learning difficulties, it was equally unusual for them to directly reject it.

I referred above to the dialogue with Deirdre about why she was in an ATC. When pressed further she said:

*I haven't any learning difficulties, I can read and write, but I've got trouble with my knee, and my ankle down there, that gives me pain.*

Direct resistance to being labelled as a person with learning difficulties was extremely rare. This may well have been because the question was not asked directly, so there was no invitation to articulate resistance. The only interviewee who did resist directly was Stella:

*Long time before I had Joanna (daughter) they said there was something wrong with me, there was nothing wrong with me, I didn't have anywhere to live and my mum wouldn't take me in, I was in and out, in and out, they thought there was things wrong with me, there was nothing wrong with me .. I was perfectly alright when I had Joanna, I didn't need to go in there at all, having her around me. The reason I went in there was cos I had a breakdown about not having her with me, see I got very depressed about it.*

Stella's situation was unusual. She said she became backward in adulthood, unlike



the others whose labels were attributed in childhood or adolescence, and she was struggling with a particularly harsh consequence, the loss of her child. The fact that she was the only black interviewee may be significant, though she seemed unaware of this. When I asked if she disliked her daughter being placed in a white family she answered: 'No, I don't like her being with a black or a white family. I want her to come home.'

Other examples of resistance were less directed at labelling per se, more at its consequences. Isobel described the oppressive regime in hospital (see chapter 8) and asserted 'I shouldn't have been there'. Her descriptions of her resistance seem to focus on the suppression of sexuality:

*Like a prison it was. You can't have a bloomin' bath, you can't go out. Boys this side girls that side. You weren't allowed to sit with them .. me and Brian used to go round the walls, bloody sister comes round. You go up your ward, you go in there she says. Used to kiss and cuddle round the corner. We got caught.*

When I asked whether she thought this was right she said 'No, cos we got told off .. cos we not allowed'. She didn't like the rules, but did not challenge their justice.

#### *Explaining auto biographies*

Relating a history of special schooling, exclusion from school, admission to hospital, gives rise to challenges to explain rather unusual life experiences. Barry described himself as having been to school when he was in fact referring to sessions held by the home tutor in his village once a week, just as Lynne told me Ridgeway was a school, though it was officially designated as an Occupation Centre.

In the course of describing their lives several people proffered explanations about why they were put in hospital. Gary said:

*I went to Bromham for me fits..with all the tablets I used to take, I*

*used to take more tablets than I do now, and I used to get very bad and shout and swear and turn nasty.*

He mentioned at another point that 'There was times when I really got stroppy and they had to throw me out of the centre.' Isobel's explanation is similar; 'I used to be ill, shout, angry, temper, I wasn't well' (she was admitted at age 13). She later added 'I shouldn't have been there.' Beryl explained Jane's being sent away thus; 'Her didn't like to work in her younger days, her use to bite the staff.' Bert's explanation was addressed in Chapter 7. For him, hospital was punishment for breaking the law.

In offering these explanations these people drew on some of the discourses informing the label 'people with learning difficulties', namely illness and transgression of certain moral codes, but they leave open the possibility that there is a normative reason too; either being ill, or, in Bert's case breaking the law. They do not directly acknowledge dependency.

Some information about attending places for people with learning difficulties was quite freely given. The 21 Club, run by MENCAP, was very popular with many of the interviewees. Malcolm, who attends no special services by choice, told me 'Another place where I go to the MENCAP place Saturday afternoon'.

Ignorance of reasons for being in special settings was claimed by some people. It came up most often when I asked for factual information. I asked Mike why he was in hospital and he answered:

*I don't know .. there's only one person knows about that, that's Simone and Roy and people like that.*

I also asked Arthur how he had come to be admitted to hospital: his reply was 'don't know'. Anna was unable to tell me how old she was when she was admitted to hospital, saying 'I couldn't know'. It is not possible to know whether these

professions of ignorance were genuine, or were a way of avoiding areas of difficulty. Silences in the interview situation can be as significant as what is said; but the interpretation of silences is not an easy matter.

### *Labelling by association*

In the course of the interviews many people used labels about others within their circle of acquaintances. We might see this either as 'labelling by association' - these people are in a similar situation to me therefore I also have the label - or as distancing mechanisms - these people are unlike me.

Some were clearly distancing themselves, and by implication asserting difference. Barry, for example, told me about local resistance to having ex-hospital residents resettled:

*Some been there all these years, they come out into a different environment, some might be self inflicted, sort of challenging behaviour sort of, some might be wandering about, they worry about the children you know.*

Isobel joined in:

*When they come outa school some might say ugh frighten children. But they could take their mothers with them, be all right then wouldn't they?*

It is perhaps ironic that Barry himself was intended for hospital care in early childhood (records of Mental Health sub Committee).

The presence of physical disability offered people the chance to distinguish themselves from others. Anna, when I asked if she went to a particular Centre said very definitely; 'No that's for the wheelchairs'. Malcolm explained his habit of helping people who had difficulties in walking with their shopping as a result of being in a wheelchair himself until he was 27. Both Eileen and Beryl told me about

helping others in the Centre; Eileen used the term 'Special Care' of the girl she helped. As Beryl said: 'There's this handicapped girl in a wheelchair, well she woulda been normal.'

Beryl also made observations on others in the Centre with particular conditions, for example of those who wear protective hats she said 'It's a shame. It advertises.'

Mike and Bert took care to distance themselves from other hospital residents, preferring to align themselves with staff. Mike in particular looked down on patients who made trouble for the nurses. He described his role as 'Helping the staff keep order, keeping the lads and lasses under control .. you don't know what the patients are like here'.

Arthur also drew a distinction between himself and other patients when I asked his opinion of the four hospitals he'd been in:

*Didn't think much of Fairfield .. we used to call it the mad house, mad people go there. Too much noise there you want quiet, don't want too much noise do you?*

(There was logic in this answer. Fairfield is a mental hospital, and Arthur was on a ward which was set aside for 'high grade' men with mental handicaps during the war.)

Malcolm consciously drew my attention to his difference from most people in his situation:

*I had no training (for independent living). Odd isn't it. Other people need training. I didn't'.*

One of the few clear statements which were distancing from association with disabled people again came from Deirdre. Not only did she deny that she had any form of disability (except a bad leg), she created a biography for her friend Kay which actively normalised her situation:

*She has step parents. I don't know what happened to her parents. They might have died in an air crash or something. But she's quite happy.*

It is not clear from these examples that people consistently used them to distance themselves from being similarly labelled. With the exception of Deirdre, most of these examples are open to the interpretation that people were using them to illustrate some of the consequences of having handicapping conditions, or, quite reasonably, pointing out differences within the large and diverse social category, people with learning difficulties. There was a tendency, however, to point out where people were perceived as less competent than the speaker, either because of physical disability or problematic behaviour.

It is unclear from the interview data whether most people accepted the label attributed to them by others, or understood why they had been labelled. There was no discernible difference between men and women in this respect. However, there is enough evidence to suggest that Edgerton's view, that people do their best to 'pass' as normal, is not entirely applicable. In some areas of discussion there may have been an inclination to 'normalise', notably in relation to schooling, but no one went so far as to reconstruct a past life which masked their experiences of being set apart - in special schools, in hospitals, remaining at home with parents well into adulthood, in long term attendance at the ATC. Most people freely accepted that they associated with people who were handicapped, disabled, or 'not normal', and by implication, I would argue, that they were themselves similarly labelled. However, they did not necessarily make the link between their label and their life circumstances. Exceptions to this were Gary, who acknowledged that he could not marry Sue, and Stella, who felt loss of her daughter was linked to her backwardness. Perhaps it is significant that these were two of those who applied a label to themselves and that the consequences they linked to it were negative.

Rather than accept that people either try to 'pass' as normal, or are so limited in intelligence that they are genuinely ignorant of their label, and its social meaning and power I would argue that they were negotiating a confusing set of messages about people with learning difficulties, who they are, why they are so labelled and what the social consequences are. Does it mean being sick, being unable to care for oneself, or others, being unable to read or write? If so, not everyone in this sample should be so labelled. Like me as an interviewer, many people avoided the issue of the label, and why it had been attributed. I felt that Gary's clarity on the matter was because his family had been open about it - but, unlike many causes of learning disability, epilepsy is a recognised medical condition. Other than Gary it is not possible to draw the conclusion that people accepted a view of themselves as dependants, whether or not they accepted the label.

### **Work and its Significance**

One role most people actively claimed was that of worker. Being in employment conveys membership of the public world. One of the expected attributes of people who are socially construed as 'dependent' is that they are excluded from paid employment (Walker 1982). Being a worker is a role expected of adults in Britain, though there are socially sanctioned exceptions, such as mothers of young children and people beyond retirement age. Dependent people, in the literature on caring, are partly dependent because they do not 'work', as the literature review (Chapter 2) demonstrates. By claiming to be a worker, people were by implication rejecting exclusion from the public world that being a dependent entails.

The experiences the interviewees had of work demonstrates that there is no clear cut demarcation line between them and others in this respect. The table below shows that a significant minority had had paid jobs.

**Table 9.1: Paid Work**

<b>Type of Work</b>	<b>Male</b>	<b>Female</b>
Factory		4
Building	2	
Domestic		1
Clerical		1
Retail	1	
Never in paid work	5	8
<b>Total</b>	<b>8</b>	<b>14</b>

If we broaden the concept of work to include unpaid work in hospitals, ATCs, volunteering and caring in the home a different picture emerges (Table 9.2).

**Table 9.2: Sheltered Employment or Voluntary Work**

<b>Type of Work</b>	<b>Male</b>	<b>Female</b>
Work at ATC	2	4
Work in Hospitals	3	2
Community volunteering	2	2
Caring work in the home	1	5
No work mentioned	1	1
<b>Total</b>	<b>8</b>	<b>14</b>

Table 9.2 shows that if the definition of work is extended beyond paid employment outside the home, it is an activity most people did.

Several interviewees indicated that work was important. Beryl explained Jane's

removal from the ATC thus: 'Her used to be one of the best workers, then she didn't want to work so she got sent away.' Gary told me he couldn't marry because he and Sue could not get 'proper jobs', and commented: 'I think the ones at Kempston, they do a proper job'. Stella speculated that loss of her child was, amongst other things, due to her being unable to get a job:

*They said I couldn't have her back. Maybe it's because I can't find any more jobs, maybe it's that, you know, I can't find any more jobs.*

Of the work people did, only paid work and voluntary work gave access to the public world. Work in hospitals and ATCs appears to represent an extension of the private domestic world, as it is both unpaid, and hidden from public sight. But it still had value for people.

Firstly I address paid work. Only Lynne had a full time 'proper job', at a laboratory. She started at a relatively advanced age, 34.

Barry worked in a Garden Centre part time. He was paid the maximum allowed before losing benefit, £12 (in 1992). He explained that his mother and brother discouraged him from working full time because of loss of benefit and liability for Community Charge.

Several other interviewees had had paid work in their lifetimes (see Table 9.1). Gender differences are not obvious. What is common to all, male and female, is that paid work was valued, yet the jobs available were unskilled manual jobs with few career prospects, low income and little job security. Bert's attempt to get a secure job in the army failed, with consequences for him that were discussed in Chapter 7.

Finding voluntary work for people with learning difficulties was currently official policy in the Social Services Department and seen as a way of enabling people to give to their community (Walmsley 1992). Arthur had a paid job prior to hospital



admission, working with his father as a hod carrier. Recently discharged from Hospital he was a volunteer in a Centre for Homeless Men. This was a Monday to Friday commitment, and structured his week, and his identity:

*Mrs. Smith said "I don't know what we'd do without you, if you didn't work here, don't know what we'd do without you, sometimes I tells me husband what a good worker you are...sweeping the yard."*

Jane worked as a volunteer in two play groups. She described it as:

*Just voluntary..do jigsaws with them and that, we make things with them, like they do painting and that sometimes to take home to their parents.*

Denise went to an old peoples' home, though her role there was unclear from her description.

The role of volunteering points up confusion surrounding the identity and competence of people with learning difficulties. They can work, but are not paid for it like other people. If the job market was different, they could also be paid. This is an economic factor, not one integral to the label. Humphries and Gordon (1992) found that half a million disabled people got jobs during World War 2, and the local evidence shows that this was true of many Bromham residents (Board of Control Annual Report on Bromham Hospital 1943).

There were gender differences in the type of work done, Jane's play group duties and Denise's role in the old people's home being classic women's caring work. However, unlike much of the caring work undertaken in the home, or in institutions, these did give access to a public world of sorts.

The majority of informants did unpaid or pocket money work within hospitals, ATCs or the home. Many of these jobs had some of the trappings of paid work. Eileen said she'd ask for the day off when I asked her to a Conference. Gary works

9 to 4 five days a week in the hospital. Beryl 'retired' from the ATC. Rita emphasised to Lynne her duty to continue to care for her father. These were not their inventions. They were part of the language people around them used, part of the structure of their daily life, part of a semblance of normality.

This work took place in hospital, ATCs, and the home. The way people talked about their work in these contexts suggests that the adult role of worker was important to them, giving them status and a role, despite the lack of pay.

The tradition of using patient labour in hospital is demonstrated in the interviewees' accounts. Here it is possible to see gender divisions, mainly in the type of work, rather than its significance. Bert used the jobs he'd had in hospital as time markers:

*I've had 3 jobs, they been good jobs. I been in the laundry six years, then I come out there I went home for a while, got a job out at Leagrave (ATC), I used to live with my youngest brother, Don, I got £1 50, I got bored with that, then I come back, I got a job in the TAC (workshop) four years, I come out there then I work with George (Hospital porter).*

As Bert's auto/biography (Chapter 7) showed, work was a significant part of his identity: 'Hod carrier, that's my trade' and 'I'm a good porter though.'

Mike told me:

*No, no I don't have a job here (hospital), I go to Biggleswade (ATC) in the mornings but I've got the day off today because they wanted help, one of the staff was off.*

He emphasised the exhausting nature of the work: 'I been working too much, that's all'.

Gary still worked in the hospital laundry, as he did when he was resident there. He was bussed there from his hostel. He worked a 9 to 4 five day week for £12: 'I

can't earn too much cos of my pension or something.' His job was sorting and packing the laundry.

Of the women, Isobel also worked in the laundry at Bromham. Barry elaborated for her: 'Big washing machines. She put the soap in. Industrial.' She and Anna also looked after children. Anna described her duties:

*I used to get up at six be there at 7 to dress 'em. Some of them can't dress themself. I used to dress one of 'em..I used to lift 'em up, carry 'em about. I didn't mind doing it, no.*

Patient labour was integral to the working of mental handicap colonies until the fifties (see Chapter 5). The evidence the interviewees gave suggests that they still had a role in manual labour associated with running large institutions - portering, laundry, helping out - and that these jobs tended to be along traditional gender lines - domestic or caring work for women, portering or labouring for men.

Four women and two men discussed working at Adult Training Centres. Mike described his work:

*We pack stuff like baked beans and carrots and all that stuff, it's amazing how we get through the stuff.*

Isobel excused herself from our first interview saying 'I gotta go to work now.'

Beryl and Eileen commented on the decline in contract work at Centres:

*Beryl: None, we ain't got none work for months and months.*

*Jan: What do you think about that?*

*Beryl: Well they ain't got find any work, only work we got's that box job Eileen's doing..*

*Jan: Which do you prefer, do you prefer working?*

*Beryl: Work like we used to do years ago, years ago we got all sorts*

*of work didn't we?*

*Eileen: Yeah. Lovely. I love doing my boxes.*

Both clearly valued contract work, low paid and repetitive though it might be, over the activities currently offered. I quoted Beryl's opinions in Chapter 5, but they are relevant here also:

*Yeah we doing cooking, I don't need to learn that..what good me learning gardening, I haven't got a garden.*

Jacqueline's mother, too, indicated that she preferred work to looking at books and doing jigsaws at the Centre. These were things she'd once done at home. Now there was no difference.

Malcolm had given up attending his Centre for similar reasons. He said:

*It's more or less what I'm doing now. I used to work at those small parts, then they dropped that off. All they doing now is woodwork, painting which I can be doing at Church Street.*

The interviewees reflect in their observations confusion around the role of Adult Training Centres. Many started in ATCs when one main activity was contract work (see Chapter 5). The emphasis in Bedfordshire was then on training and education, but, as some interviewees testified, contract work continued, and where it did not, the activities on offer were seen merely as ways of passing the time. Most seemed to value the idea of doing a job, and there was little distinction between men and women, either in the work they did, or in their attitude to it.

The home was also the site of work, particularly caring and domestic work. Several women recalled caring for parents in later life (see Chapter 8). Deirdre told me; 'I was the only one that looked after her (mum). She had cancer in the stomach.' and Denise emphasised her mother's dependence on her:

*She couldn't help herself, you know. I used to say "you gonna eat that?" I used to say "nice dinner". But she wouldn't eat it, you see. I couldn't go anywhere.*

Eileen, Lynne and Barry still took responsibility for caring for parents. For all three it was a 'double shift' combined with work at the ATC and/or outside. The ambivalence some women felt about these responsibilities has been examined in Chapter 8, and the extent to which domestic duties were described to me as work varied. For example, Denise told me: 'I don't do nothing, only the housework and washing and that'. Barry was the only man to emphasise caring for someone else in the home, though Malcolm dwelt at some length on his own competence in domestic work.

The two mothers whose children lived with them also had a caring responsibility within the home, and Stella wanted that too. Caring for children appeared to carry a less ambiguous status than caring for elderly parents, though was still a private rather than a public activity.

Work in the home loomed more prominently in the way women described their lives than men. I commented in Chapter 6 on the tendency for women to be expected to undertake more domestic work for themselves than men, but this expectation appeared to have been internalised by them so that Denise dismissed her housework as insignificant.

These accounts of the work people do suggest that the role of worker was a significant one, described in language which masked its insularity and its privatised nature. What they also had in common was economic dependence. Lynne, despite having a full time wage, handed over most of her money to her father as board money and it was symbolically returned to her to do the shopping. Eileen told me: 'No my dad does that. I'd love to. He might let me, if anything happens to him, one day.' Denise's 'pension' was controlled by her home help and her aunt. Barry was

discouraged from increasing his income from work because it would lead to liability for poll tax and loss of benefit. Gary could only earn £12 a week because it would affect his 'pension'. Bert got £1.50 a week for packing curlers. Stella paid her money to her mother. People could work, they could make an economic contribution, but they could not be paid adequately for doing that work, partly also because they were socially structured as dependants. Even Lynne, with her 'proper job', did not control her wages.

Being a worker, in ATCs, hospitals, as volunteers was something people valued. This finding is in line with other research (Noonan Walsh 1991, National Development Team 1992, Eaton 1994) which emphasises the significance of work for self esteem and social contacts. Worker was the most common conventional adult role mentioned. It is important to recognise that people with learning difficulties feel they are making a contribution through work, and the value they give to the mundane activities associated with ATC contract work casts doubt on the recent policy of making ATCs places for education rather than work.

This examination of how people present work and the role of worker in their lives, illustrates how they try to make sense of what is a confusion about their identity. As dependent people they should be incapable of making an economic or social contribution to society. Yet this was not so. Many did work of some economic value; often incidentally, this was caring work - contributing to the welfare of parents, children, friends, peers. They were inheritors of a tradition of putting the poor to work, a tradition which stretches back to the Elizabethan Poor Law - workhouses, labour on roads, the roundsmen system are all examples of the poor being required to work in return for state financial support. Specifically both hospitals and ATCs have a history of being places where patients are taught the value of work and its disciplines as well as being required to be economically productive. The practice of voluntary work in the community was but a recent

example of this practice.

### *Men and Women - Gendered Identities?*

In this final section I consider how men and women present themselves as gendered beings. In any context gender is significant for personal identity, though, as I commented in Chapters 2 and 5, the label of 'person with learning difficulties' has tended to be pre-eminent in the way people have been viewed in research and policy, and their biological sex has not been seen as important, at least since overtly eugenic ideology and practice have been abandoned.

Gender is also important in relation to debates about caring. The literature discussed in Chapter 2 clearly points to the ambiguity of caring as an activity women are expected to take on, and often embrace voluntarily, yet is undervalued, both financially and socially. For women who are seen as dependants caring has an additional dimension, a valuable activity from which many are excluded, yet one which may represent exploitation.

Throughout the data analysis chapters I have commented on gender differences, and similarities. Already in this chapter I have noted how men give less emphasis to the significance of the domestic and caring work they do in the home. In Chapter 7 Bert's tendency to romanticise his relationships with female staff, and his stereotypical masculine activities - boxing and weight training - were noted. In Chapter 8 I suggested that women found their immediate relationships with close family members more restrictive than men, and that caring roles were not optional for women as they were for men.

Whilst gender differences in the way the label learning difficulties was negotiated and in attitudes to work are hard to discern, there was a clear tendency for men to describe themselves as active in making choices for themselves, whilst the majority of women appeared passive, and saw themselves acting at the behest of others,

something Atkinson and Williams found also (1990). This was exhibited both in major life events, and in day to day contexts, such as travelling independently.

I noted in Chapter 7 that Bert described his return to hospital after a brief stay in 'the community' as his choice:

*The money was alright, ten pounds a week you know, but I got a good job here with George so I jacked it in, you know.*

Malcolm told me he was actively seeking to move back to his home area in the north:

*I got a note out with me brother to look for a place for me .. I could go up for a week, I know the housing manager wants to see me.*

Barry talked of his plans for the future: 'Not being nasty you know, but when me mum goes I'd like to live with Isobel, yeah'. He described the work he did for his mother as his own choice:

*She's getting on, she's 72, she sort of relies on me, I do shopping, a little bit of gardening, sort of thing.*

This impression of being able to make choices was not universally true of the men interviewed. Gary, as described earlier in this chapter, accepted that being handicapped meant he needed to be looked after, and could not get a 'proper job', and David seemed to feel helpless in the face of his family's refusal to have him home.

Of the women only Beryl and Sheila gave the impression that they were making their own choices. The rest of the women appeared passive in the face of plans being made for them by others. Lynne was able to assert her wish to live alone 'before I get too old', but had no strategies for achieving this, other than saying so. Eileen's future with her sister was mapped out for her, after her father died, and though she acknowledged a group home might be nicer: 'I don't like to hurt me



sister'. Denise was frustrated with waiting for her promised job as mini bus escort, but felt powerless in the absence of any action by the staff concerned. Stella railed against the loss of her daughter, yet felt both powerless and ignorant: 'No one ever explained to me why they took her away .. they say no I can't have her back at all, I don't know why.'

It was also noticeable that men moved around more freely than women. Bert was allowed to cycle around the local area; his girlfriend Yvonne could only go out in the grounds with a nurse. Barry left the ATC whenever he wished. In contrast, I had to ask permission of several people to interview Eileen, at the same ATC. Gary went out to clubs and classes in the evening; Eileen and Jacqueline were picked up by a coach to go to the Club and Deirdre did not go out at night at all for fear of mugging (Chapter 6).

Whilst men and women with learning difficulties are often subject to decisions about them being made by others with little consultation or even explanation, it is worth noting that the men interviewed were more inclined to describe themselves as having some power and some choices, whilst most women accepted the constraints imposed by others, although some were able to assert that these were emphatically not their own choices. It is impossible to say whether the men were potentially as free as they claimed, or whether the women were as powerless, though the freedom to move around did seem to be greater for men. What I can say is that women were more inclined to acknowledge dependency on the decisions of others than men, and more inclined to accept limitations on their freedom of movement.

There are indications that involvement in self advocacy may have played a part in giving Malcolm and Barry the confidence they displayed in their own capacity to make decisions. Only four of the interviewees had any direct connection with self advocacy. These were Beryl, Isobel, Barry and Malcolm. Amongst the others

awareness was low. Eileen, for example, did not know what it meant. It emerged clearly that the two men who were most confident in their ability to make their own choices were also the two people who operated most extensively outside the domestic sphere of home and segregated service provision, largely through membership of self advocacy groups. Both Malcolm and Barry were active in self advocacy groups; both had been to the national People First Conference in Twickenham in 1991; both were also active in the 'community', Barry on the local Users' Forum and Malcolm in his own philanthropic activities described in Chapter 8. The two women were less involved in self advocacy. Isobel went to the *Speaking Up* Group with Barry and Malcolm, but had nothing to say about it. Beryl was on the ATC Users' Committee, and told me about raising money to redecorate the coffee area - a private rather than a public activity. These findings tally with those of Thomson and McCarthy (forthcoming) who assert that 'almost all the self advocacy groups (we) have come into contact with have been dominated by men'. The indications are that in mixed self advocacy groups, men are more likely to emerge as the dominant figures

#### *Opposite sex relationships*

Finally I focus on relationships with the opposite sex, because it is an area where sexual identities are actively played out. As no one acknowledged any homosexual attraction or activity, I can only say in passing that this is unsurprising, and bears out the little research so far undertaken that it is something people with learning difficulties are reluctant to discuss (Burns 1992, Thomson and McCarthy forthcoming).

In terms of marriage and publicly celebrated sexual relationships the majority of people with learning difficulties are set apart. Historically they have been discouraged from marriage and parenthood and the effects of this prohibition is exhibited in this research. Only ten of the 22 interviewees claimed to have had any

close relationship with a member of the opposite sex in their lifetimes.

Beryl believed that people in the Centre were discouraged from sexual relationships:

*They stop it a little bit. One girl, she got sent to Silsoe so she lost her boyfriend.*

She made no direct link to her own experience, merely answering when I asked if she had a boyfriend: 'No, don't want one'. Three men gave answers when talking about relationships with women which allied them to the world of men.

*Malcolm: 'One question I were asked "Do you like living on your own?". You know what I come up with? "Better than women nagging at me". It is really isn't it?*

*Mike: Me and Bert's too busy chatting up the ladies, my dear.*

*Bert: I ain't found the right one yet.*

These answers give a distinct impression that being single is a personal choice, not a consequence of their social situation. The comments are consistent with Mike's claims to be a chivalrous protector to the nurses, and Bert's stories about his flirtations with hospital staff, and also with the observation that men were inclined to present themselves as having and making choices.

Two men were in romantic relationships with women. Barry and Isobel had a close relationship which they implied was sexual. Isobel described their week together in a caravan: 'Went off to the bedroom together, went off to sleep me and Barry did'. Barry claimed he was prevented by his obligations to his mother from marrying, possibly a reason that non labelled men might give if they were caring for an elderly parent. It was, however, at variance with what Beryl told me after one interview (not taped) that his mother and brother would not let him marry. This is perhaps the most direct evidence that some interviewees were inclined to interpret

events as if they were able to make adult choices when in fact they were being denied them by others. This contrasts with Gary, who said he couldn't marry because he and Sue have fits. Both Barry and Gary expressed a wish to care for their girlfriends. Barry said he gave Isobel confidence in the interview. Gary shopped for Sue, and looked after her when she had fits, as she did for him.

It is perhaps worth noting that the men I discuss here expressed their caring side in relationship to girlfriends, fiancés and potential girlfriends and struck protective, almost chivalrous attitudes to these women. I was the recipient of Mike's chivalry. He escorted me to my car after one interview and told me that if I had trouble with my husband I could call on him!

The majority of women, including three of the mothers, claimed no current interest in men. Eileen shyly told me of a boyfriend, Christopher, but was unable to tell me where and when they met. For Denise, Beryl, Anna, Jacqueline and Jane such relationships with males were, and as far as I could tell, always had been, non-existent.

Of the women who did have men friends, Lynne presented her relationship with Eddie as practical rather than romantic. She would not marry Eddie because he was 'too old'. Two women spoke with relish and enthusiasm about their boyfriends. One of these was Isobel whose exploits in hospital and whose relationship with Barry have already been described in other contexts; though it is worth adding here that Isobel had been sterilised after leaving hospital, with her consent. As she described it to me:

*Then I went in Luton and Dunstable Hospital. Operation. Sterilised.  
.. Long while ago, Mr. Brown down the Centre, he says "Isobel, you  
don't want a baby" Mr. Brown went up there, he said "I don't want  
Isobel to have that baby". Took me in the clinic and test me. Yeah,  
I'm all right, I'm on pills. Oh God, God, temper tantrums, throwing*

*things, I can't remember anybody, it's those tablets. When I went in the clinic me blood pressure was up high. You know what it was, it was them pills. I'm not taking them any more. Then they took me in hospital, then I'm all right. Dr. Harris operated. 10 hours I was underneath.*

The other, Denise, talked of marriage with keen anticipation:

*When I get married that's where I'd like to live. His name's George. I met him in the hostel. He works in a pub. I says "I'll be glad when we're married". He says "I will when I've got enough money". Money. Bloomin well hurry up then. First he says he wants to get married, then he says he does, then he says he don't. I've been out with him long enough, nearly a year now, two or three years I think since I been out with George. Age don't worry me. Doesn't matter how old they are. I know he's a little bit younger than me, but it doesn't matter to me. (George is 32, Denise is 49).*

I wrote in my notes at the time that marriage appeared to be Denise's goal, regardless of who with. The sense of frustration this extract conveys is a contrast to Barry's expressed certainty of his intentions towards Isobel, again characteristic of the active men / passive women picture painted above.

Sexuality and sexual relationships were not topics which most people discussed with me. Where they did, there was a distinct tendency by men to present the single state as a choice, not a consequence of being labelled. Gary was again the exception. Proportionately fewer women expressed interest in developing relationships with men. Denise's rather stereotyped attitude to marriage was unique amongst the women. Isobel, strikingly, emphasised her sexual history in her interview, and dwelt on the injustices of the hospital system in its unsuccessful attempts to restrain her from contact with the opposite sex. But most professed

contentment with the way things were, and expressed their need to care for others in relation to family, friends and other service users, rather than in heterosexual dyads.

## **Conclusion**

This discussion of personal identity, as labelled people, as workers and as men and women reiterates the findings in Chapters 7 and 8 that most people rejected a simple view of themselves as dependent people. In their answers to my questions people presented images of themselves which were complex and multi-faceted, answers which conveyed to me a rounded picture of human beings struggling to make sense of their situations and their relationships.

The apparently low awareness of themselves as people carrying a stigmatised label is perhaps the most noteworthy finding. For the most part being labelled was a taboo subject. It suggests that families and staff have failed to discuss with people the fact that they have been labelled and treated accordingly. Paradoxically, although this enabled people to present to me a relatively normal identity, it also deprived them of tools with which they could begin to understand the singularity of their lifestyles and the oppression they experienced. Instead most played the game they had learnt, that their label was a subject to be avoided and that they should use language and terms which masked their differences from the mainstream. The impact of this is seen in relation to work. They used terms - day off, pension, retirement - which are associated with paid work, but most worked, if at all, for negligible reward and with little public recognition.

It may be that these findings in relation to work and labelling are linked to the principle of normalisation which advocates that people have access to normal patterns of daily life (Nirje 1969). It would be hard to argue that the lives of the four people in hospital, for example, do approximate to normal patterns, whatever they may be. The principle is adhered to to the extent that people are encouraged to

describe themselves and their lives as if they are 'normal'. If this is the case, perhaps normalisation is itself oppressive rather than liberating, serving to maintain the status quo, and harnessing peoples' eagerness to preserve self respect to support that.

Finally, in relation to gender the findings support Brown and Smith's (1992) argument that normalisation tends to reproduce existing gender inequalities. The evidence suggests that women with learning difficulties are subjected to expectations that as women they will care for themselves, and others. Yet here there may be a double oppression, because these caring responsibilities are neither publicly recognised, nor do they give ready access to paid employment. Although not universally the case, some men appeared to have benefited from self advocacy and the opportunities it offers for a public life and identity, whereas none of the women had done so. Men moved around freely, women were more constrained, often fearful of going out at night. Yet men also faced an additional challenge of maintaining a masculine identity whilst being subject to the dictates of mainly female staff. This seemed to be less problematic for women who could more readily normalise relationships with staff into friendships or helping relationships. Both men and women have apparently been constrained in developing sexual relationships, but proportionately more men had developed a sense of themselves as potential sexual partners than women, a finding perhaps linked to men's tendency to present themselves as active in making choices, whatever the reality of the situation.

The dimensions of identity, social and personal, are complex. Here I have explored what can be deduced from biographical interviews with a group of adults with learning difficulties. In Chapter 10 I summarise the research findings as a whole.

## **Chapter 10: Findings and Areas for Further Research**

### **Introduction**

This chapter summarises the research findings and identifies where further research is indicated.

The thesis I proposed to test was that asking adults with learning difficulties to describe their experiences of care and caring would generate new perspectives on an established area of social research. The research was designed to discover the way people with learning difficulties understand care and caring, and to contextualise their understandings in their biographies and in the way services for people with learning difficulties have developed in Luton during their lifetimes. I sought to challenge some assumptions about the status of people with learning difficulties as dependants and to show that they are in a more complex situation in relation to caring than that simple formulation implies.

The importance of care and caring as the research focus is that dependence on the care of others implies exclusion from productive roles in society, roles which are associated with adulthood and full citizenship (Oliver 1990, Johnson 1993). Being a carer potentially accords more status and power than being a dependent, though paradoxically, being a carer can also marginalise people, and women's caring responsibilities for family members have been identified as a barrier to citizenship (Lister 1990, 1992). The possibility that women with learning difficulties, usually regarded as dependent on the care of others, are also care-givers creates a paradox. The role of carer, although undervalued according to Lister and others, has greater status than that of dependent. Yet if these women are caregivers they may be open to similar, or greater, marginalisation than other female carers.

Furthermore, the apparent dichotomy between carer and dependent is questioned by this research. Research by Morris (1993a) in relation to disability, and by some



gerontologists (Walker 1982, Wenger 1984) casts doubt on the carer/dependent polarity common in research into unpaid family care, and suggests that people involved in such activities do not recognise themselves as 'carers' or 'dependants', and that reciprocity and interdependence are features of most 'caring' relationships. Sixsmith (1986), also in the context of gerontology, found that older people valued physical independence, autonomy in making choices, and reciprocity. This research also casts light on the fluidity and complexity of caring relationships.

Using primarily data from biographical interviews with 22 adults with learning difficulties I set out to discover how these people described and experienced care and caring. The biographical interviews were supplemented by historical research including examination of primary and secondary sources relating to the local history of learning disability, and oral history interviews. The results of this historical research provide both a context for the lives of the interviewees, and a history of the way learning disability services developed in Luton in the second half of the twentieth century.

I begin with the method and identify its strengths and weaknesses as a means of testing the thesis. I then discuss the findings. These are based on a small sample and therefore further research may be necessary. Areas for further research are indicated where appropriate. Finally, I discuss the overall significance, and some practical implications the research findings have.

Each of the major points is summarised in italics, and then developed in more detail.

## **The Method**

The research set out to test the use of biographical interviews with people with learning difficulties as a means of finding out about their lives, and about their understandings of care and caring. Specifically in the Introduction I set out two

methodological hypotheses, namely that adults with learning difficulties have a valuable and valid contribution to make to research into care and caring, and to historical research. Below I evaluate the method and present some methodological findings related to these hypotheses.

### **Findings related to the hypotheses**

*Biographical interviews with people with learning difficulties have the capacity to generate data which sheds light on their understanding of abstractions such as care and caring and demonstrate that they have a contribution to make to research in that area.*

Although people did not respond directly to questions about care and caring, the information they gave did generate a range of perspectives which challenge existing orthodoxies about the nature of relationships between ‘carers’ and ‘cared for’ from the point of view of the ‘cared for’.

This is an example of research which acts as ‘an important antidote to accounts which come from other quarters’ (Atkinson and Williams 1990:8). It is hard to imagine other methods which could have generated the findings presented here. The one biographical interview where a parent was present (with Mrs. M and Jacqueline) produced answers which were at such variance from the other interviews as to suggest that parents have a perspective on care and caring which is significantly different to that of adults with learning difficulties, a finding which is consistent with the arguments for the method I put forward in Chapter 3.

I set out to give pride of place to the words of the interviewees. It was my decision to treat interviewees as people whose words could be trusted. When I began the research this seemed a bold strategy as many earlier studies had incorporated data from a variety of sources (Flynn 1986, 1989, Atkinson 1986, 1989), but this has since become an increasing focus for research (Stuart 1992, Simons 1992, Atkinson

1993 a,b,c, Booth and Booth 1994, McCarthy in progress). Whilst such an approach may be open to criticism that it presents a subjective picture, this seems justified because much research on learning disability has discounted the views of people with learning difficulties (see Chapter 2 Section 3 for some examples). As it happened I came across evidence which corroborated some facts I was given, and some evidence that people put a particular gloss on events which was at variance with evidence from other sources. The validity of what people told me was not compromised by these incidental cross checks.

I made some adaptations to standard life history interview techniques to improve peoples' understanding of the research and what I found out about their lives, for example the illustrated information sheet, the written 'story', and replaying the tape with the interviewee. These adaptations were effective but not adequate to include people with little speech. This is a reflection of the limited time I had available to conduct the interviews and my own lack of skills in sign language, facilitated communication and other techniques developed to communicate without recourse to speech and writing. It is an area where future research may be valuable.

*As a means of generating historical information individual biographical interviews with adults with learning difficulties have a valuable contribution, and are especially informative when combined with other sources.*

The biographical interviews furnished insights into the subjective experience of administrative practices which are absent from the documentary evidence. The research shows that it is particularly important in research into learning disability to combine documentary and oral history methods as the history of the local and national services is little researched; and the surviving records document only the perspectives of administrators, staff and families, not those of people with learning difficulties.

Some interviewees provided full accounts of the main events of their lives. This

includes three of the four selected auto/biographies in Chapter 7. Others were less informative in this respect, and there was a degree of frustration for me in trying to piece together the life maps. The reasons for the variation appear to include factors associated with the interview relationship, for example a failure on my part to establish a relationship which encouraged disclosure, or poor communication skills on both sides of the interview; choices made by the interviewee - a deliberate wish to forget the past, or to avoid areas of difficulty; or genuine ignorance of what happened and the reasons for it, often combined with an undeveloped concept of time.

The result was that any attempts I made to analyse the data to construct typical 'careers' along the lines developed by researchers into the life course (Elder 1974, Bertaux 1981, Humphrey 1993) were frustrated, and I drew the conclusion that the method, biographical interviews, was not in itself enough to draw such definite conclusions.

Some of the individual interviews included reminiscences which are of historical value, and help to illustrate how social forces shape individual's biographies. However, unlike the oral history interviews I conducted with a parent and three professionals, few interviewees with learning difficulties demonstrated awareness of the wider forces which have shaped their lives. The historical research played an important role in enabling me to put lives in a context of changing policies and attitudes over time, and to make some links between the personal and the social. This finding is in keeping with advice to oral historians to familiarise themselves with the historical context before undertaking interviews (Thompson 1988).

### **Other Methodological Findings**

In addition to these findings related to the research hypotheses, it is important to record some other points. These are described below.

*Gaining access to interviewees with learning difficulties as an outsider required the researcher to work through intermediaries. This had an impact on the way the research was conducted.*

My lack of direct access to adults with learning difficulties meant I initially had to approach potential interviewees through others. In instances where the interviewee had his or her own home direct negotiation between interviewer and interviewee was rarely a problem. Where the interviewee lived with parents or in residential care, however, negotiations to speak to the person, and to meet could be complex. This meant I could not control the way the research was initially presented to people; that consent could not be directly negotiated with interviewees; and occasionally that the circumstances in which the interview was conducted were not chosen by either the interviewee or interviewer. Issues such as these demonstrate the lack of autonomy possessed by some adults with learning difficulties, and the significance of peoples' living circumstances for their freedom of action. (This aspect of the research is explored in more detail in Walmsley 1993b).

*The way the sample was constructed had strengths and weaknesses.*

Working through intermediaries and existing interviewees to make contact with other interviewees meant that I did not adhere to my original intention of interviewing a single age cohort. A range of ages and different living circumstances meant that these variables could inform the analysis. However, this generated a large number of potential categories, and there were small numbers in each - one man living with his family, one man living independently, one woman in hospital, one black woman - and conclusions drawn from these single examples are of necessity tentative. Further research with a larger sample into the experiences of people in some categories, such as middle aged men living at home with their families, would be of value.

*Ownership of the research by interviewees was partial.*

Issues of ownership have been aired extensively in the literature on qualitative research (see Chapter 3). The method used here incorporated strategies to allow interviewees to own their individual accounts, for example to amend the 'stories' I wrote. This allowed people to clarify and correct the information based on their individual testimonies but did not permit involvement in the subsequent analysis of the data obtained from all the interviews. There is a tension in sharing interview data obtained from individuals with guarantees of confidentiality with a group of people who have only their label in common, a tension which can be partly overcome in research where the interviews are conducted with a group (see Potts and Fido 1991, Atkinson 1993a and b).

*Confidentiality was not absolute*

Confidentiality was compromised for two principal reasons. The first was that it was sometimes difficult to detach people from staff or, in one case, a parent to speak to them in private. This involvement of 'carers' indicates an attitude that peoples' lives are public property, and that they have no right to privacy.

The second reason was that the records of the Mental Deficiency Committee and the Mental Health sub Committee archived in the County Record Office contain names and other details which make it possible to identify individuals with ease. Again, this appears to reflect a low value placed on the right of people with learning difficulties to privacy.

*Including others in the interviews at the request of the interviewee enriched the research findings.*

Several interviewees asked for a second person - friend or member of staff - to be present during the interview, a wish which I always agreed to. This contrasts with much advice on conducting oral history interviews where it is argued that one to

one interviews are preferable (Thompson 1988). The case for flexibility rests both on the possibility of obtaining more and different information, and on respect for the interviewee's wishes.

Ensuring that the presence of a third person is the interviewee's own choice was, however, a matter of delicate negotiation. In some cases, such as with Mrs. M and Jacqueline, it was not possible to offer a choice to Jacqueline herself. As this, and other instances quoted in this research demonstrate, the presence of a third person alters the interview dynamics and influences the information obtained. It also allows the interviewer to observe the relationship which can enrich the findings, particularly when the research is about relationships.

### **The Research Findings**

The thesis was that asking adults with learning difficulties to describe their experiences of care and caring will generate new perspectives on an established area of social research. The findings are linked to the hypotheses set out in the Introduction, Chapter 1.

*Adults with learning difficulties do not talk about their lives in terms of care and dependency*

This hypothesis proved to be valid. Only two interviewees openly described themselves as in need of being looked after, in both cases by residential staff. The majority of interviewees identified themselves as people who help or look after others in a variety of contexts

Furthermore, only a minority of interviewees described themselves as having learning difficulties, being disabled or handicapped. This finding corresponds with the work of Edgerton (1967), and Jenkins and Aull Davies (1991), but is at odds with Simon's research into self advocacy (1993) where labelling was a focus of discussion. The reasons for peoples' reticence on the subject of labelling are

unclear. There was little evidence that people hid facts about their biographies to enable them to 'pass' as normal as Edgerton claimed, but there was a recognisable tendency to use language which masked difference from the norm. For example, euphemisms such as 'keep an eye on me' (Beryl) were used to acknowledge the need for assistance in daily living; and unpaid work in institutions or in a voluntary capacity was described using terms which normalise it, words such as 'retirement', 'pension', 'job'. This appears to reflect the silence maintained by both families and staff on the stigma of being labelled as a person with learning difficulties, a practice associated with normalisation (Chappell 1992). It also indicates a lack of collective identity as people with learning difficulties. The relative weakness of self advocacy in the interviewees' lives may also explain the contrast with Simon's findings (1992), and may reflect a limitation in the sample.

The fact that the only interviewee who identified himself as 'handicapped' was one of the two people who described a need to be 'looked after' may be significant. It suggests that there may be a correlation between seeing oneself as disabled, and accepting the need to be cared for. The assumption that the two are linked is embedded in much of the research into care. Further research which specifically explores this sort of correlation would be worthwhile.

However, while few interviewees talked of dependency, objectively most were at least financially dependent. Money often symbolised the balance of power within relationships. Parents retained control of their sons' and daughters' incomes whilst they lived at home, and in some cases after they had left home. Residential staff firmly controlled the money people had to spend even on relatively small items such as cigarettes. Financial dependence was expressed in particular language - Gary spoke of his father giving him 'pocket money', and benefit income was described as a 'pension' by three respondents. The few people who had financial autonomy - Beryl, Alanna and Malcolm - were all independent householders. All



indicated limitations on their freedom caused by low benefit levels and poverty. The exception to the rule of poverty was Sheila, the only married interviewee.

*Adults with learning difficulties see themselves as caregivers as well as recipients of care*

This hypothesis also proved to be valid, although it was complicated by the fact that none of the interviewees used the terms 'care', 'caregiver' or 'recipient of care'.

Care and caring are embodied within relationships. The people I interviewed did not use the word 'care' in the way it is used by service providers and academics, as a commodity or as a descriptor of services. Indeed, no one used the terms 'care' or 'caring' at all in the interviews. When asked directly what 'care' meant it was defined specifically as expressions of affection. When interviewees discussed relationships in which tending or assistance was given or received they used the terms 'looking after' or 'helping'. 'Looking after' implied an intimate non reciprocal relationship. 'Helping' implied a relationship in which there was reciprocity, usually in less intimate relationships. I found no equivalent language to describe negative or abusive relationships. This was largely an area where silence was maintained, though when they were described it was invariably through anecdotes - telling a story.

Family relationships included examples of interviewees acting both as caregivers and recipients of care, but these relationships were not characterised by reciprocity. Within families it was hard for people to negotiate adult status and to make choices. People who were living with families, or in close proximity to them, described conflict over going out, bringing up children, control of their own finances and personal relationships. These tensions were most keenly felt by women, though this may be because few men were in daily contact with families. Interviewees' accounts suggest that parents did not adjust attitudes to their daughters even when they became to some extent dependent on the daughters' contributions to the

household. The extent to which care for parents was seen as a burden varied. Of six women who were at one time in this position four described it positively; two spoke of it as burdensome. In this respect the research confirms some other research into caring for elderly relatives, such as that undertaken by Lewis and Meredith (1988) and Qureshi and Walker (1989). Several interviewees were positive about the independence they acquired on the death of the parent they lived with.

People who had lost key family members, especially parents, described relationships with them more positively. This was also true of people whose families lived at a distance. Visits and being included in family events were highly valued by people living in residential care, and people regretted it when their families failed to keep in regular contact with them.

Friendships - both same sex and heterosexual - were relationships where reciprocity and interdependence were most readily identifiable. Again, there are instances of caregiving between friends, but overall these relationships were characterised by give and take. In one case where friendship included elements of 'looking after' another person the one who did the looking after exercised some control over the other person.

Reciprocity in relationships with front line staff was valued by a substantial number of interviewees. Both men and women described situations in which they helped staff. Staff who taught specific skills or provided assistance with discreet tasks such as writing cheques, cooking, speech therapy were singled out for mention. Two interviewees appreciated a more general 'looking after' function performed by residential staff, but these were the exception.

As peoples' experiences of caregiving were significantly mediated by gender, and other biographical factors, these discussions are continued below.

*Gender will mediate the experiences the experiences adults with learning difficulties have of care and dependency, and the way they describe these experiences.*

Gender was significant in the way people experienced care and caring; as were age, biographical factors, and possibly race. The willingness of the majority of female interviewees to describe caring and nurturing relationships suggests that they had internalised a sense of caring as women's work (Graham 1983), although their living circumstances were such that caring for sexual partners and children was unusual, and caring was more frequently undertaken in relation to friends, older parents or other service users.

Caring for parents was associated with older interviewees who remained in their parental homes until the second surviving parent died. This was a trend which was also found in the historical evidence. Most of the interviewees who cared for elderly parents were women, though that may indicate a bias in the sample in which, the majority were women *and* more men lived in residential care. Although some women actively sought caring responsibilities in relation to friends and other service users, and within families, taking on some responsibility for caring for elderly parents appeared to be something which was not negotiable. This was associated with the status of single daughter at home who is ideally placed to become the principal family carer (Lewis and Meredith 1988). In two cases the care was shared with paid staff - home care assistants and home aides - and relationships between the daughter and these paid carers could be fraught. This is an area which could benefit from further exploration as the causes of the tensions were unclear.

Becoming a carer for a parent did not bring a change of status in other respects. Two women spoke of restrictions on going out; two described continuing financial dependence.

Men also took on caring roles, but invariably represented this as a choice. Only one

man was providing help to a parent; others cared, or attempted to do so, within heterosexual partnerships. As all but two men lived in residential care where their domestic needs were met by paid staff and who therefore had fewer opportunities to perform 'tending' tasks for others, this is an area which requires further research.

Parenthood was something few interviewees had experienced. For those who were parents, four younger women, the experience was contradictory. All valued being a parent, but the involvement of mothers in child rearing created conflict, and two of the four had lost custody of their children whilst a third felt her own mother wanted other arrangements for bringing up her son. As Booth and Booth's study (1994) shows, it is not unusual for women to have their competence as parents challenged by others.

Within friendships women indicated reciprocity through shared domestic responsibilities. Men's friendships with other men were less common, and more readily characterised as companionship and shared interests in leisure activities.

In relationships with staff female interviewees identified themselves as helping to care for other service users, usually people who needed more physical care than they did. Men laid less emphasis on nurturing roles in relation to other service users, and instead described themselves in terms of recognised jobs such as portering or tasks requiring physical strength such as keeping order. Women's relationships with female staff were sometimes described in terms of the reciprocal obligations of friendship. Men's relationships with female care staff in residential accommodation appeared to polarise between maternal or sexual models. However, this is an area where further research would be advisable as there were few women in residential care in this sample, and a specific focus on the impact of gender on relationships between service users and staff in different roles - residential care, day services, social work - might yield interesting results.

The research raises, but does not begin to answer, questions about racist

assumptions on the part of service providers. The only mother to have lost her child against her will was black; as Bryan, Dadzie and Scafe (1985:113) show, black women are particularly vulnerable to having children removed by social workers. This woman was also being treated for schizophrenia; again, disproportionate numbers of black women are diagnosed as mentally ill (Bryan Dadzie and Scafe 1985:119). There is little research into the experiences of black women with learning difficulties (Baxter, Poonia, Ward and Nadirshaw 1990), and a specific focus on this subject is an area which urgently requires investigation.

*The social identity of people with learning difficulties is culturally and historically specific*

In trying to assess this hypothesis I examined the interplay between social and personal factors in the life course. The research clearly demonstrates that policy on learning disability structured the lives of individual interviewees in a variety of ways. The only route to a home of their own, for example, was through the failure of family care, or through motherhood. In the absence of alternatives, other than hospital, the majority of interviewees lived with their parents well into adult life, and the usual reasons for leaving home were death of a parent or other family breakdown. The naturalness of this was not challenged by anyone I interviewed; and both mothers of adults with learning difficulties I interviewed regarded family or family type care as the optimum. A minority of people set up their own households immediately after leaving the family home. These included the four mothers, all under 40, Malcolm, Beryl and Denise. The majority moved into other care environments, family or residential, although some later became independent householders.

The impact of services on interviewees' lives varied according to age and gender. More men lived in residential care than women, which may reflect an assumption that men are less able to look after their own domestic needs, although it is possible

that this was a quirk in the sample rather than a statistical trend. Women were therefore more likely to be self reliant in day to day living than men, and had more opportunities to be proficient in domestic tasks, a finding which tallies with Noonan Walsh's research (1988). The younger women, under 40, all established their own households in their early twenties: none of the older interviewees had done this, but the fact that the younger women were all parents almost definitely had a bearing on this, as it did on their not being included in day services. On the other hand, the absence of any parents over 40 in the sample may reflect changing attitudes to sexuality and parenting amongst service providers and families. Anecdotal evidence suggested that their children invariably were taken away from mothers with learning difficulties well into the seventies.

The rarity of sexual partnerships reflects attitudes to sexuality and parenting for people with learning difficulties, attitudes which many interviewees apparently internalised. The majority of interviewees did not discuss the absence of a sexual partner, although a small number aspired to marriage.

A fairly vigorous and close knit community of people with learning difficulties and their families was the consequence of the segregated and stable services, and the network fostered by MENCAP and its Club reinforced this sense of community. There were advantages for those people who had grown up with this environment in terms of a sense of belonging and familiarity. The people who were outside this network, primarily non ATC users, were more socially isolated and came into contact with fewer people on a regular basis. The stability of the community had, however, limited peoples' opportunities for change and for relationships with people who were neither family, staff or other people with learning difficulties, an effect of segregated services which has been noted in a number of research projects (see Atkinson and Williams P 1990 for an overview of the literature on social networks). However, there was no evidence that people outside the community

fostered by the ATC, hostel and 21 Club had developed a wide range of social contacts to compensate, a finding which casts some doubt on current policies of dispersing day and residential care throughout the town. Similar studies in other geographical areas may shed more light on the impact of segregated services on peoples' social networks.

In terms of further research I suggest that historical research of the type I undertook in other geographical areas is urgently needed. I know of no similar local study with which to make comparisons.

*Families have had a central and contradictory role in relation to care and adults with learning difficulties*

The research showed the central role families of origin played in the lives of the people I interviewed. On the one hand, loss of family, particularly at an early age, subjected people to a series of fluctuations in fashion related to preferred living arrangements, most clearly illustrated by Anna's life. On the other hand, staying in the family home, or in close proximity to it, often entailed frustration and a loss of opportunities for autonomy and adult roles. The role was contradictory in the sense that families were both an actual and potential source of nurture and support, and a barrier to autonomy and a sense of adulthood.

The historical research showed changes in the way family care was viewed over time. The shift from regarding families as a source of eugenic contamination to being the ideal care environment occurred in the early nineteen fifties, and remained the ideological cornerstone of learning disability services until the early nineties when the research took place. In practice, families provided the bulk of care throughout the century, and the post war changes were in part rhetorical. In part, though, they were the product of an increasing mobilisation of parents' demands, and a recognition that institutional care was both expensive and undesirable (HMSO 1957, Stainton 1992a). Day services designed as adjuncts to

help families continue to bear the responsibility for their sons and daughters grew inexorably in the post war decades (though there are signs that this growth has now ceased). This had a paradoxical impact. The numbers of children on the hospital waiting lists reduced dramatically with the inception of Occupation Centres (French 1972), but the numbers resident in Bromham Hospital continued to increase until the late 1960s (French 1972). This appears to have been the consequence of more people being assessed as deficient (later subnormal), and the local authority's failure to provide residential facilities until the early seventies.

The idea that people need care remained constant, although the views on optimum care environments changed during the period 1913 to 1992. In practice in Bedfordshire there was always resistance to institutionalisation both from families and from members of the Mental Deficiency Committee, though from the late nineteen thirties to the 1960s medical professionals vigorously defended the role of the Hospital.

Services at the time of interviews had the twin roles of supplementing family care through day services, or replacing it with family type environments if the family could not provide 'care'. The research suggests that more resources and attention were targeted at people who had recently left hospital than at people living at home with families, on the tacit assumption that people living with parents could safely be left to manage.

In relation to the role of families in the lives of adults with learning difficulties, the research overall suggests that family care was valued by adults with learning difficulties if it was expressed as affection rather than as 'looking after'. Looking back, some, but not all, adults who had lost family regarded family life with nostalgia. For people in residential care or living alone families represented a sense of belonging, contact and being supported. Living with or near to family at the time of interviews produced more mixed reactions. Perhaps it is most accurate to say that



the alternatives to family care were in many cases unattractive. It may be that living alone in the community without a network of supportive friends or staff was no substitute for life, however infantilised, within the family.

### **Other Findings**

As I argued in Chapter 1, specifying hypotheses at the outset of exploratory qualitative research is somewhat speculative. In the event, most of the findings related to the original hypotheses. Two other findings are described here which were not anticipated when the research was framed. The first of these relates to gender.

*Men described themselves as active in making choices; women presented a more passive image.*

There were differences in the way men and women talked about themselves. Men laid emphasis on their autonomy, presenting situations in which they made the choices, even where their circumstances meant their degree of choice was probably very limited. Few women put themselves at the centre of their own stories. Most regarded themselves as people for whom choices were made, even when they manifestly disagreed with those choices.

Associated with this was the greater likelihood that men moved around freely whilst women relied on others to transport them. The involvement of two men in prominent roles in self advocacy, and more public roles associated with self advocacy activities confirms the suggestions made by Noonan Walsh (1988) that men with learning difficulties receive greater encouragement than women in developing skills associated with developing a life beyond the confines of home or service setting. It also demonstrates a continuity with the past when some men were permitted to leave the hospital grounds to work or visit the town whilst women were confined to the hospital (Annual Report on Bromham Hospital 1943).

The second unanticipated finding relates to the role of the community in caring.

*Care by and with the community is in its infancy in Luton*

Twenty years after Bayley articulated the concepts of care by and with the community (1973) there was virtually no evidence that the interviewees experienced a wider caring community beyond the segregated community of people with learning difficulties, their families, and specialist staff. Only one interviewee spoke of abuse - physical and verbal - from passers by, but the more telling evidence is the absence of people other than friends with learning difficulties, service users, staff and families in the networks of relationships people described. Work - paid and voluntary - outside service settings was the principal vehicle for wider social contacts. None of these represented more than casual acquaintances. Some interactions with shopkeepers, the library, and the like were mentioned, but they played an insignificant part in most peoples' lives.

**Overall Significance of the Findings**

In discussing the overall significance of the findings I refer both to the content and the method.

The research demonstrates that people with learning difficulties have a particular perspective on caring relationships which is at variance to the perspectives of families, or staff. The theme that caring for people with learning difficulties is a lifelong burden which is so prevalent in the research literature (see Chapter 2 Section 3) finds no place here.

The research bears out Jenny Morris's contention (1993a) that carers and cared for do not recognise themselves as such, and that polarisation of the two groups is unhelpful and misleading. Caring relationships are complex and multi faceted. Recognition that care and dependency are part of a continuum, and that they change over time, allows us to acknowledge diversity. The interviewees may be seen by

others as the subjects of an abstraction called 'care', but they see themselves as in relationships, and it is only possible to come to an understanding of what is meant by care and how it is experienced through asking about relationships.

Relationships are complex, more complex than a transaction involving care as a commodity. This bears out Qureshi and Walker's definition of care as a relationship (1989), and the arguments within gerontology and disability that interdependence and reciprocity are features of relationships between so-called 'dependants' and 'carers' which those crude labels obscure (Oliver 1990, Keith 1992, Johnson 1993).

However, there is a danger that such re-evaluations of relationships between dependants and carers obscure real discrepancies in power. It is possible to argue that this research demonstrates increasing interdependence between parents and adults with learning difficulties as parents age; but this was not accompanied by commensurate changes in attitude or control over matters such as money and freedom of movement. Adults with learning difficulties are well placed to become carers for older parents if they remain in the parental home after siblings leave, and they have few reasons to resist pressure to do so on the grounds of paid employment or other family responsibilities. As people excluded from other caring roles, especially for their own children, caring for parents may appear a valuable opportunity, especially to women. Yet there is considerable potential for exploitation, and few opportunities for people to transfer any skills or experience thus gained to paid work. The research suggests that women are particularly vulnerable to being pushed into caring roles in the home, partly from their own volition, partly because of pressure from family and staff, partly out of a sense of obligation to the parent. This indicates the importance of awareness for policy and practitioners of the dangers of gender stereotyping and the risks of reproducing, in exaggerated form, existing gender inequalities in society.

The findings of this research are of relevance to the ongoing debate over

citizenship, women and caring. If being a carer limits women's citizenship, the position espoused by Lister (1990, 1992), where do women with learning difficulties fit? The role of carer is arguably on the basis of this research one which was more attractive to women than the role of dependant. Yet it had the potential to lock them into positions where their contributions were ongoing, sometimes burdensome, and unrecognised by others. There is a contradiction here which existing theoretical models do not address, based as they are on the belief that carers and dependants are watertight and exclusive categories. It is not only a matter of recognising that carers and their dependants have different, and often conflicting, rights (as argued by Ungerson 1993). It is also necessary to address the interrelationships of gender, disability and caring, an enterprise which this research has only begun to tackle.

The importance of friendship with other people with learning difficulties bears out Richardson and Ritchie's findings (1989). Whilst within a normalisation framework such friendships are seen as secondary to more desirable friendships with people who are not stigmatised, the friendliness of the women who had neither shared living arrangements nor ATC network suggests that segregated services do have an important role in facilitating friendships.

Women's friendships with other women were particularly significant sources of intimacy, companionship and mutual care. It is important not to over-idealise women's friendships. Reciprocity was not necessarily present, particularly where one of the women was a caregiver. This is a message that is important for service providers. Inviting people to bring a friend to reviews and assessments is regarded as good practice (Brechin and Swain 1987), but the existing relationship between the two may influence what is said.

What people said about staff raises some interesting issues. That people value staff who offer practical help, who allow themselves to be helped, who make it possible

to talk things through, and who are humorous echoes Simon's findings (1992). Perhaps, though, more interest lies in the way people make sense of relationships with staff in the absence of an open acknowledgement of being different. Thus various models were detectable in the way people described relationships with staff - the friend, the pal, the potential sexual partner, the mother figure, the oppressor. The first three may reflect the impact of normalisation training in which staff are encouraged to be friends to their clients (Middleton 1988, Brechin and Swain 1989, O'Rourke 1992). There is considerable potential for confusion and disappointment in trying to fit staff/client interactions into a normalised framework, one that seems particularly acute for men in relation to female residential staff.

The impact of normalisation principles on peoples' lives seems to have been quite significant, and not always positive. It is most obvious in peoples' coyness about their labels. I am certain that the majority of interviewees were not ignorant of being different, contrary to what Jenkins and Aull Davies suggest (1991). However, the majority did not have the language to talk about it. Efforts to normalise activities such as work in the ATC or hospital by reference to jobs, wages, retirement etc. seems to have been a joint enterprise by all involved. There is an argument that this benefited people by enabling them to present their lives to outsiders such as I in a positive light. Nevertheless, most people had lives which were impoverished in many respects - poverty, few opportunities to develop new interests or new relationships, to travel, to earn money, to experiment with different lifestyles. These limitations seem in large part attributable to being labelled and treated accordingly, but only two interviewees articulated awareness of those links. The polite silence maintained by families and staff alike on the fact that people carry a stigmatised label apparently deprived them of the tools and opportunities to make sense of their experiences and inhibited the development of collective resistance. Those people who did resist oppression did so as individuals, not as part

of a group, and were relatively powerless as a result. Seen in this light normalisation individualises the experience of living as a disabled person. Simon's research into self advocacy (1992) demonstrates that a sense of the oppressive effects of being labelled can develop in groups; the weakness of self advocacy amongst the interviewees may be both cause and effect of these interviewees' low level of awareness.

The research also offers an opportunity to re-examine the role of family care. The historical research showed that family care became idealised in the post World War Two period, and remained the core assumption upon which policy and practice were based (Abbott 1990). People were not offered alternatives unless and until their families failed in some way to provide care. This served to keep costs down. The rhetoric of family care served the interests of those who provide and pay for services well, but arguably at the expense of both families and adults with learning difficulties who remained locked together for better or worse. Continuing to live in the family home into adulthood, or continued dependence on parents seemed to infantilise people; hence the frustrations expressed by some interviewees. However, alternatives to family life were often bleak, meaning that family care looked desirable in retrospect, or from a distance. There was also a two tier service which disadvantaged people living with their families. Attempts were being made during the period the research took place to offer comfortable group homes and opportunities for voluntary work to hospital leavers like Arthur (Walmsley 1992), but such initiatives were not open to people who lived at home with their families.

Finally, the research shows that regarding people with learning difficulties as dependants is a crude generalisation which masks many individual differences; and yet poverty, discrimination, and social prejudice have combined to create dependency and exclude people from full participation in society at a number of levels. In this research I concentrated on the views of the 'cared for'; other research

shows that carers also experience poverty and exclusion. Setting the interests of carers and cared for against one another, as much research into informal caring appears to do, blurs the common interests of both parties. I hope others will build on this research to shape policies which will benefit both sides of caring relationships.

## **Appendix 1**

### **Brief Biographical Details of the Interviewees with Learning Difficulties**

#### **Introduction**

This Appendix is provided so that readers can find the biographical details of the 22 interviewees with ease. The information includes information on date of birth, age at time of interview, place of birth, where known, residence at the time of the interview, experience of paid or voluntary work, previous places of residence, involvement in self advocacy, parents' occupation, where known, and whether parents were living at the time of the interview. Except where mentioned, the interviewees are all unmarried and childless.

The information is from the Life Maps derived from the interview data (see Chapter 4). Although this sounds a straightforward task, as I explained in Chapter 4 the nature of the interview data was such that in many cases details are missing, or unclear. There is therefore a risk of representing as fact the bare bones of peoples' biographies. The reader must accept that these potted histories are the product of a reconstitution of subjective interview data, and as such often inadequate accounts. For example, my lack of knowledge of parents' occupation does not mean that it is lost information, simply that I failed to elicit it.

The interviewees are listed in alphabetical order for convenient reference. Pseudonyms are used as in the data analysis chapters.



### *Alison*

Alison was born in 1962, aged 30 at the interview date. She was born in London, whence her family moved to Luton when she was a baby. She went to a mainstream primary school, and then to a Special Secondary School. She married at 18, to escape her abusing father, and had three children by her first husband, all of whom were adopted. She was divorced, then remarried and had three more children. These were in the process of being adopted at the time of the interview. She had separated from and later divorced her second husband, but was living in his house as a lodger at the date of the interview. She had had some employment in a factory - at the date of the interview was not employed. Parents' occupation unknown. Her mother was alive, but estranged from Alison, her father had died in 1990.

### *Alanna*

Alanna was in her thirties, unmarried. She lived in her own rented home with her illegitimate son, aged 15. She was born in Luton. Her father was a Vauxhall worker, and subsequently self employed. She went to a number of schools including a special school, a state primary and two boarding schools. She had two jobs in her teens, as an assistant in a hotel kitchen and as a ward domestic in a hospital. Parents were both alive separated, and in regular contact with both Alison and one another. One brother lived in Australia, another lived locally, but they met rarely.

### *Anna*

Anna was aged 52, born in 1940 in Bristol. She lost her family at an early age, and may well have been fostered. She entered hospital in early adulthood and helped on the children's ward. Since leaving hospital she had lived in two hostels, at least, and was currently resident in a privately owned and run home for six people in Luton.

She was a daily attender at Bramingham. Her parents' occupations are unknown to me. No contact with family.

### *Arthur*

Arthur was born in 1929, aged 62 at the time of the interview. He was born in Peterborough and went to a local primary school. His mother died of TB when he was at school. On leaving school he worked with his father as a hod carrier and as a lorry driver's mate. The story then becomes confused. His father died and he went into hospital, though Arthur was not explicit about a causal link, or even the chronology. He lived in four different mental handicap hospitals, the last being Fairfield, Bedfordshire. In 1990 he had left hospital, and been resettled in Luton in a group home run by a voluntary organisation (with Gordon, another interviewee). He was a volunteer helper at a Centre for homeless men five days a week, the result of a Project Redpact initiative. His father had been in the army, and his mother a stay at home housewife. He has some contact with his stepmother and brother and sister.

### *Barry*

Barry was born in 1945, was 46 when interviewed. He lived at home with his mother and brother in the Bedfordshire village where he was born and has lived all his life. He went to classes in his village run by the home teacher for children who were excluded from school as ineducable. After leaving this 'school' he spent a period at home until Bramingham Centre opened. He was one of the first intake into Bramingham, and had been attending for 25 years. He had also a part time job at a local Garden Centre, paid therapeutic wages. He was a member of the local Users Forum, a consultative body set up by Social Services. He also went to the local Speaking Up Group based at the Adult Education Centre in Church Street,

and had been to the 1991 National People First Conference in Twickenham. His parents' occupation is unknown, though it is known that his father spent some time in Fairfield Psychiatric Hospital. His father is now dead.

### *Bert*

Bert was born in 1937 and was aged 55 in 1992. He was living in Bromham Hospital at the time of the interview. He was born in Luton, went to a special school and was put under 'friendly supervision' when he left. He had jobs in the building trade as a hod carrier. He tried to enter the army but was rejected on health grounds. In his early twenties he was sent to Leavesden Hospital after a criminal offence, and subsequently was sent by the Magistrate's Court to Magull, a Special Hospital near Liverpool, after a second offence. He went from Magull to Bromham Hospital when his period in Magull ended. In hospital he had several unpaid jobs in the workshop (TAC), and as a porter. He had had two spells out of hospital, neither of which had been permanent. His father was in the army, as was at least one of his brothers for a time. Both parents are now dead. He has regular contact with one brother, and irregular contact with his other brother (local) and sister in the USA.

### *Beryl*

Beryl was born in 1931, was approaching 60 when interviewed. She lives alone in a council flat. She did not go to school, and stayed at home in Luton with her parents until her mother died in 1965, five years after the death of her father. She then went briefly to live with her brother, and subsequently returned to live in the family house. In 1966 she went to Bramingham Centre, only months after it opened, and has remained there ever since. When her brother died in 1985 she moved into her flat. She was about to retire from the ATC in 1992, and reduce her attendance to

two days a week. Her father worked in the dye works in Luton, her mother was a housewife

### *David*

David was born in 1950, aged 42 at the time of the interview. He was born in Luton and was schooled at a special boarding school. He attended Bramingham Centre for a period, before going into Bromham Hospital where he was still living. The occupation of his parents is not known. Both parents are alive and living in Luton with David's sister who also has learning difficulties and goes to Bramingham Centre. He has only sporadic contact with his parents and lived for a time with his brother in between spells in Hospital.

### *Denise*

Denise was born in 1943, aged 49 at the date of the interview. She was born in a village outside Luton and as far as I know she did not go to school. She lived there with her parents until her mother died. She then briefly found a home with her sister, then went into a hostel. Thence she moved (circa 1991) to live with a much younger woman in a new group home run by a voluntary organisation. Although this group home is unstaffed it is next door to a staffed group home, and staff there take some responsibility for her well being. She is part of Project Redpact which provides her with some outings and opportunities to socialise with other people with learning difficulties, mostly older men who have recently left hospital. Parents' occupation unknown. Her sister takes an active interest in her welfare.

### *Deirdre*

Deirdre was born in 1937, aged 55 at the interview. She was born in Berkshire and as far as is known did not go to school. However, she worked for many years as a

messenger or clerk in the Admiralty at Datchet. She moved with her parents to Luton, apparently after being invalided out of her job because of a knee injury. She went to Bramingham Centre whilst still living with her parents. When her mother died she briefly stayed in her home, but was later moved to a group home where she was living with another woman with learning difficulties at the time of the interview. Her parents' occupation is unknown. Her parents died within two years of one another. She is in regular contact with an aunt.

### *Eileen*

Eileen was born in 1951, aged 41 at the interview date. She was born in Luton and has lived in the same house with her family all her life. She went to Special School in Luton, and when she left went to Bramingham in the year it opened, 1966. Her mother died soon after that. She still goes to Bramingham five days a week and lives with her father. Her father was a milkman, her mother worked at on the till at a supermarket checkout. She sees her married sister weekly, and this sister has offered her a home after her father dies.

### *Gary*

Gary was born in 1949, aged 43 at the interview date. He was born in Luton and went to boarding schools in Shropshire and in Kent. He went to Bramingham after leaving school, and was later admitted to Bromham Hospital. He had left Bromham in about 1988 and lived when I met him in a large (14 bed) private hostel in a large town in Bedfordshire. He worked for therapeutic wages in the Hospital as a laundry worker. His mother was a market stall trader, father (divorced) occupation unknown. His father visits him fortnightly, his mother, now married for a third time, takes him home at weekends, and he has frequent contact with brothers, sisters and his step families.

### *Gordon*

Gordon was born in 1922, aged 70 at the time of the interviews. He was born in Harpenden, the son of a restaurateur and hotelier, and went to primary school (at least) in Harpenden. His family moved around a good deal, and he had lived in Wales and London. He had been a resident of Fairfield Hospital, though when and why he went there is not known. In 1990 he was resettled into a group home run by a voluntary organisation where Arthur also lives. He spends his days in the staffed group home. He has no contact with any of his family.

### *Isobel*

Isobel was born in Essex in 1944, aged 47 at the time of the interviews. She probably did not go to school, and was living in Luton at the age of 13 when admitted to Bromham Hospital where she looked after the Superintendent's young children and later worked in the laundry. She left Bromham (date unknown) to go into Wauluds hostel. Around that time she was sterilised. She then began to attend Bramingham Centre where she met her boyfriend, Barry. At the date of the first interview she was living in the Wauluds Annexe, in preparation for moving to a staffed group home run by a voluntary organisation. She was living there at the time of our third meeting. She was a member of the Speaking Up Group based at Church Street. Parents' occupation unknown. Both are still alive, living in Essex, and have regular, but infrequent contact with Isobel.

### *Jacqueline*

Jacqueline was born in 1949 in Luton, aged 43 at the date of interview. She lived with her eighty year old mother in a council flat in Luton. She had been excluded from school, put on statutory supervision and went to the Kirby Road Occupation Centre from the age of 8. She began to attend Bramingham Centre when it opened,

and was still a five day a week attender there. Her father was a bank clerk, had died 25 years earlier, at which point she and her mother moved from central to north Luton. (After the interview her mother was taken ill, and later died, and she moved into the private group home where Anna lives). There was contact with some members of the family. especially a married nephew living locally.

### *Jane*

Jane was born in 1949, aged 43 at the date of the interview. She is a Lutonian, had gone to a private school in a small town in Bedfordshire. When she left she went to Bramingham, until her mother died in about 1974 when she went into Bromham Hospital. Subsequently she lived in a hostel in Bedford, then a group home, and finally got her own flat in Luton, near where her father lives, and three doors away from Beryl. She then resumed a place at Bramingham, and also worked as a volunteer at a play group for half a day a week. (After our interviews she got another voluntary job at a play group for children with special needs). Her father worked at Vauxhall Motors. She saw her father, brothers and sisters regularly, and baby-sat for nieces and nephews.

### *Janette*

Janette was born in 1958 in Luton, aged 36 at the interview date. She was living in hospital, and visiting her parents every weekend. I know no more of her history.

### *Lynne*

Lynne was born in 1949 in Luton, aged 43 at the date of the interview. She was put under statutory supervision and did not go to school. She went to the Ridgeway Occupation Centre as a child, and later to Bramingham when it opened in 1966. In 1983 she obtained a job at a pharmaceuticals factory near her home where she was

working at the time of the interview. She continued to live with her father in a council flat (though he has since died and she stayed in the flat on her own). Her father worked in a chemical factory before retirement. Her married sister now lives in Yorkshire, and rarely visits.

### *Malcolm*

Malcolm was born in 1947, aged 44 at the interview date. He had been born in Nottinghamshire, and gone into hospital there when his family broke up through divorce. Subsequently he had lived in a hostel, then left to live with his father in Luton when his father remarried. In 1983 his father died and he remained in the flat where they had both lived. He has had no paid jobs, but had created a helping role in relation to disabled people he knew through the Training Centre. He had chosen not to continue attending the Centre. He is involved in the Speaking Up group, and had been to the 1991 People First National Conference with Barry. Parents' occupation not known. He is in contact with siblings, all of whom live in north Notts/ south Yorkshire, and he hopes to move back to live near them.

### *Mike*

Mike was born in 1962, in Luton, aged 30 at the date of interview. He went to Special School in Luton and entered a hostel after leaving school. At the time of the interview he had been resident in Bromham Hospital for several months, following a violent outburst on the death of his father. He was a four day a week attender at an ATC in Bedfordshire. His mother was still alive and worked as a cleaner. He was also in contact with his brother who still lived with their mother in Luton.



### *Stella*

Stella was born in 1962, 30 at the date of the interview. She originated from London and moved to Luton in early childhood. She went to mainstream schools. After leaving school she continued to live with her parents in a rented house in Luton, and had a number of unskilled jobs in factories. At age 22 she had a child out of wedlock, and moved into a council flat with the child. The child was removed from her when she was about 3 years old, and eventually placed in a foster home with a view to adoption. After her daughter was removed she became mentally ill, and spent several periods in Fairfield Psychiatric Hospital, diagnosed as schizophrenic. She was at the time of the interview unemployed and living in a one roomed council flat in north Luton. Her father is Jamaican and at one time owned a small farm there, but was currently unemployed. Mother's occupation unknown. She saw her mother three or four times a week, visited her father frequently, and also regularly met the father of her child, now remarried and with a child of that marriage.

### *Sheila*

Sheila was born in 1953 in a village outside Luton, aged 38 at the time of the interviews. She had a speech problem as a child and was sent from the special primary school she attended until age 8 to a special boarding school where she received intensive speech therapy. On leaving school her mother had helped her get work in a sewing workshop and later in a factory. At age 20 she married a man living in the same street and they set up home together in a council house in a Luton suburb. She had five children ranging in age from 18 to 6, all but one of whom was in special education locally. She was currently a full time wife and mother, and the only one of the interviewees who had passed a driving test. Her mother died in 1990, her father lived nearby. Parents' occupation unknown. She

had fairly frequent contact with her brother in law and sister in law, and her own sister.

## Appendix 2

### Example of a Story presented to Interviewees after the Research Interviews

#### Eileen's Story

Eileen was born in Luton in 1951. Her dad was a milkman and her mum worked in Fine Fare (now Gateway). She went to Richmond Hill School where she enjoyed doing sums. When she was 15 she left school to start work at Bramingham Adult Training Centre which had just opened. She is now one of the oldest inhabitants of the Centre. She has been there for over 25 years.

When she was 16 Eileen's mother died. This is the saddest event in her life. She says:

*I still miss her after all this time.*

This left Eileen at home with her sister, Pam, and her dad. In the 1970s Pam married and left home, though she does not live far away. She keeps in touch at least once a week.

Now Eileen lives at home with her dad. She likes to look after her dad:

*I do the shopping for him and the washing up. I do me own washing .. I think me dad needs me. I leave him for a weekend. I have to leave him for a week soon. I hope he manages all right. I don't think I'll ever leave him, not unless anything happens to him.*

Recently, both Eileen's dad and Eileen have been ill. Eileen's dad was ill first. When dad was very ill Eileen had to do lots of work. She did the shopping by

herself, and the cooking. This she found quite hard: *when I got it to the table it was cold.*

Her sister also helped out. Eileen remembers how she felt:

*Oh, I didn't mind. Just kept an eye on him and kept plodding along.*

Some good things came out of this. Before that time Eileen's house had no hot water, no bath, no phone and a very old cooker:

*Oh, it was dreadful for years and years until last year someone did something about it, we had hot water and everything.*

While Eileen's dad was ill the social worker got to work and managed to get hot water laid on, a bath, a cooker and a phone. This made things easier for Eileen and her dad.

#### *What Eileen enjoys*

Eileen enjoys doing jigsaw and making rugs. She also likes reading, though has not done much lately. She spends a lot of time with Beryl, her friend. She stays at Beryl's at weekends, and they go shopping together, watch TV and do jigsaws. Beryl made her a cake for her 40th birthday. They help one another. Once they went on holiday together, to Kessingland.

On Wednesday evenings she goes to the Club where she used to meet Christopher, her boyfriend. Christopher no longer goes to the Club, so she doesn't see him any more.

Eileen works at the Centre. She makes boxes for paints. She used to like doing blocks and making hinges, but they do not do that any more now.

Eileen also enjoys helping people. She helps her dad as much as she can. She used to help people at the Centre, pushing wheelchairs to the toilet and the dining hall. She hasn't done this since she was ill. When I asked why she likes helping she said: *I enjoy it, I just do it naturally, you know.*

### *The Future*

Eileen does not know what she will do in the future. She says:

*If anything happens to my dad I think I'll be living with my sister. My sister says she's got a place up there, I can stay with her, live with her. That's nice, cos I could help her then, couldn't I?*

Carol, her key worker, says when she's better she'll go to another part of the Centre with work more suited to her ability. She also thinks she might like to go to a Group Home but isn't sure that she can tell her sister:

*She might be upset.*

*This story was obtained from Eileen in three interviews, one with Beryl, in May, June and October 1991.*

## **Appendix 3**

### **Notes on the Historical Sources**

#### **Documentary Sources housed in the Bedfordshire County Record Office**

These County Record Office sources are described in two sections, the first appertaining to the work of the Mental Deficiency Committee 1913-1946, and the Bromham House Joint Board 1930-1946. In 1946 these two bodies were dissolved and the work of the Mental Deficiency Committee was taken over by the Mental Health (sometimes referred to as Mental Treatment) sub committee of the County Council. The second section therefore comprises the post war records, 1946 to 1972. Records after 1972 were not available in 1992 as they were embargoed under the 20 year rule.

In Chapter 5, and elsewhere, I have referenced the CRO sources using initials of the source (MDM - Mental Deficiency Committee Minutes, for example), the volume number and the date. The meanings of these initials are explained below.

#### **Section 1 Records of the Bedfordshire Mental Deficiency Committee 1913-1946**

The task of the Mental Deficiency Committee was 'To carry out all the powers and duties of the County Council under the Mental Deficiency Acts 1913 and 1927 and to report their proceedings annually to the County Council, or more frequently if they saw fit' (Bedfordshire County Council Year Book 1936-7).

The Committee was serviced by a Clerk, and met quarterly. Its records are archived in four categories:

### **MDC (General Correspondence)**

These are extant for the period 1914-1948 and contain copies of all the Clerk's correspondence. They contain examples of correspondence with families over certification, leave of absence from institutions, removal to institutions, assessment of parental contributions for maintenance and arrears chasing; letters to institutions requesting information on availability of places, costs, reports on individual patients.

### **MDL (Letter Books)**

These are extant from 1915 to 1922, and 1929 to 1941. They partly duplicate the MDC series, with the major difference being that they comprise only outgoing correspondence. They are filed in strictly date order, being mostly wet copies of MDC.

### **MDP (Clerk's papers)**

These are extant from 1915 to 1947. They are the source I used most frequently as they contain copies of circulars (for example from the Board of Control and the National Association for the Care and Control of the Feeble Minded), internally circulated notes and memos, rough drafts of committee minutes, all reports received from the Deputy medical Officer of health and the Voluntary Visitor of their visits to the homes of defectives and their families, copies of Board of Control Inspectors' reports on Bromham House, circular letters from institutions advertising availability of places and their costs, reports from institutions on Bedfordshire inmates, statistical information on the numbers and whereabouts of certified defectives, updated quarterly, and other miscellaneous items. They are filed in roughly date order, and appear to comprise all information received by

the Clerk, and some drafts of his replies. Unlike the Minutes, all names and addresses are present.

### **MDM (Committee Minutes)**

These are the formal Committee Agendas and Minutes, and duplicate the information found in MDC, MDL and MDP. Names of defectives and their families are recorded only as initials, and there are no addresses. They are less informative than MDP.

### *Bromham House Joint Board Papers*

Bromham House was set up jointly by Bedfordshire County Council, Northamptonshire County Council and Northampton Borough Council. The Joint Board met from 1930 to 1946. It comprised elected representatives of the three local authorities, with the Medical Superintendent of the Hospital in attendance. It was serviced by a Clerk.

Its duties were taken over by the North West Metropolitan Regional Health Authority in 1946.

I made less use of this series than of the Mental Deficiency Committee papers because hospital life as such was of less relevance to the research.

### **JBC (Joint Board Correspondence)**

These are extant for the period 1929-1949, and comprise initially correspondence about the construction of the hospital. From 1932 onwards, when the first inmates were taken on, the series includes correspondence between the local authorities about admissions and discharges, staffing,



expansion of accommodation, institutional routines, purchasing of supplies and equipment.

**JBL (Joint Board Letterbooks)**

Like the MDL series, these duplicate MDC, being copies of the Clerks correspondence in date order. They exist in a continuous series from 1930 to 1948.

**JBP (Joint Board Papers)**

These are the clerk's working papers, potentially a rich source for historians of the hospital. They exist from 1930 to 1942.

**JBM (Joint Board Minutes)**

These are the formal minutes of the Board, like MDM using initials rather than full names for defectives. They exist from 1930 to 1948.

**JBV5 (Board of Control Reports)**

This series comprises the Annual Reports of the Board of Control's inspectors on Bromham Hospital from 1931 to 1948.

**JBV14 (Individual Case Files)**

This series comprises correspondence relating to individual patients from the late 1930s and early 1940s. They appear to be an accidental survival, and do not represent all the patients then resident at the time. They are a potentially valuable resource for reconstruction of individual biographies as they include correspondence with families, and professional reports on individuals.

## **Section 2 Records of the Mental Health Sub Committee 1946 to 1969**

The Mental Health Sub Committee took over from the Mental Deficiency Committee in 1946/7. Its remit included mental illness as well as mental deficiency. Its membership was partly elected and partly ex officio and there is evidence in the early papers (He /Sub P 6/1) that there was some lobbying for representation from nurses. It was serviced by a Clerk. Its papers are archived as follows:

### **He / Sub P (Papers of the Mental Health Sub Committee)**

Like the MDP series described above, this is the clerk's working file, containing correspondence, circulars, statistics, reports from the Deputy County Medical Officer of Health on individuals (to 1951 only: after 1951 these are summarised and made anonymous), reports from Mental Welfare Officers, Board of Control inspection reports on Occupation Centres, staff appointments, salaries, terms and conditions, training, reports from elected members on visits to Occupation Centres, papers relating to plans for new facilities, individual payments to guardians, reports on defectives in the care of the Brighton Guardianship Society, place of safety orders and other miscellaneous items. Three of the five files were available to me: He Sub P 6/1 June 1947 to June 1948; He Sub P 6/2 October 1948 to October 1952; and He Sub P 6/3 January 1953 to December 1962. He Sub p 6/4 covering Feb. 1964 to November 1970 was not available for consultation.

There was relatively less information kept as the fifties progressed, and even less in the sixties, reflecting the decreasing influence of the Committee as professionals increased in number and influence, and presumably began to hold information elsewhere.

## **He Sub M (Minutes of the Mental Health Sub Committee)**

Like the MDM and JBM series, these are the formal printed minutes of the Committee, and duplicate the information found in He Sub P (papers). All defectives' names are concealed. Three volumes were consulted, H Sub M 6/1, 2 and 3, covering the period 1947 to 1969.

### **Secondary Sources**

Secondary sources consulted range from general histories of Bedfordshire and Luton to local reports and publications on social services, health and education, through to specialist publications on learning disability. These are listed in the References Section.

The most useful sources were:

#### *Charles Tomlinson's Problem Families in Luton, 1946*

Commissioned by the Eugenics Society, this was one of five such studies undertaken in the late 1940s. In the Preface Tomlinson mentions the support and encouragement of prominent figures associated with the Eugenics Society, CP Blacker and Richard Titmuss. The Report defined problem families as those who need 'a substantially greater degree of supervision and help over longer periods than is usually provided by social services' (p.11). With the help of health visitors he discovered 251 problem families, representing one in every 200 families, and one in every 100 individuals in the town (p.13). He identified 'subnormal mental capacity' as one of a number of causal factors creating these problem families. As a piece of contemporary social research its assumptions are of particular relevance to this research as it is roughly contemporary with the date of birth or early childhood years of most of the interviewees.

*Cecil French's History of the Mental Health Services in Bedfordshire 1946 to 1971*

This is a professional's account of the expansion of the scope of professionals, and the increase in the provision made for people with mental handicaps and mental illness. As a basic text with dates and statistics relating to the expansion of community services in the post war years it was of great value. It is generally optimistic in its outlook, suggesting an underlying belief that things were improving, and as such is similar to Jones's contemporary national *History of the Mental Health Services* (1972). In view of the fact that I interviewed Cecil French 20 years after this publication, his memory was remarkably consistent. For example, he used the same words to describe the impact of the establishment of Occupation Centres on waiting lists for hospitals in his interview as he had written in his book.

*Luton Society Year Books 1960 to 1992.*

These were loaned to me by Rene Harris from her personal collection of documents relating to the local branch of the National Association for Backward Children, later MENCAP, and enabled me to trace the changing preoccupations and attitudes of the Luton Society from its early years to the present. The Year Books contain articles about local facilities - Hospital, Occupation Centres, schools and Training Centres-, reports of holiday visits, letters from parents, photographs as well as news items on fund raising, Christmas parties and other social events.

*Bedfordshire Health Authority's Joint Consultative Committee's Plan for Services for People with a Mental Handicap 1988 to 1994.*

This document includes an overview of provision for people with mental handicaps in the county in 1986-7, and sets out a strategic plan for the county's services in the period during which this research took place.

## **Appendix 4**

### **A brief history of learning disability in England and Wales 1913 to 1992**

#### **Introduction**

This appendix provides a context for Chapter 5, and the thesis generally, in delineating the major landmarks in policy for people with learning difficulties in England in the twentieth century. Cross references are made with the thesis findings where possible. The account begins with the passage of the 1913 Mental Deficiency Act.

#### **The 1913 Mental Deficiency Act**

The Mental Deficiency Act laid down the framework within which mental deficiency was to be handled for much of the twentieth century. It was not fully superseded until the 1959 Mental Health Act. Other legislation such as the 1927 Mental Deficiency Act and the 1946 National Health Service Act (see below) influenced its operation and implementation but it continued to be the legislative framework throughout the period.

In 1908 the Royal Commission on the Care and Control of the Feeble Minded reported. Its findings were that there were 149,628 defectives, of whom 44.45% were 'unquestionably in need of provision either in their own interest or in the interests of public safety' (Simmonds 1978:392). The exceptional fecundity of feeble minded women was a particular preoccupation. The 1913 Act was influenced by the Royal Commission's belief that feeble mindedness was growing, and posed a major social problem. The Act was the product of a sustained campaign co-ordinated by the National Association for the Care of the Feeble Minded and the

Eugenics Education Society (Williams and Walmsley 1990). It was inspired by two major motives, care and control. Care was one side of the pincer movement. Heart rending stories of undefended defectives in the care of careless or vicious people flew around (Jones 1972:196-7); at the same time there was a moral panic about the dangers to society of increasing numbers of degenerates if the less desirable members of the population were allowed to procreate at will. The Act defined categories of mental defectives as follows:

'Idiots' the lowest grade - 'persons so deeply defective in mind as to be unable to guard against common physical dangers'.

'Imbeciles' - 'incapable of managing themselves or their affairs or in the case of children being taught to do so'.

'Feeble minded' - adults whose condition was 'so pronounced that they require protection for their own protection or the protection of others' i.e. a social condition, though for children the criterion was educational 'appear to be permanently incapable of receiving proper benefit from the instruction in ordinary schools'.

'Moral defectives' - persons who from an early age displayed 'some permanent mental defect coupled with strong vicious or criminal propensities on which punishment has little or no effect', i.e. different in kind from the rest.

(Jones 1972:204-5).

People became 'subject to be dealt with' under the Act if;

- 1 a low grade (idiot or imbecile) and parents petitioned the Local Authority

- 2 any grade under 21 whose parent or guardian petitioned the L.A
- 3 if defective in any grade and
  - i) neglected, abandoned, cruelly treated or without visible means of support
  - ii) guilty of a criminal offence or liable to be sent by a court order to a certified industrial school
  - iii) in prison, reformatory or industrial school, lunatic asylum or inebriate reformatory
  - iv) an habitual drunkard within the meaning of the Inebriates' Acts 1897-1900
  - v) if incapable of receiving benefit from attendance at a special school; if presence in such a school was detrimental to others; or if attained age of 16 at Special School and the Board of Education certified that further care was required
  - vi) in receipt of poor relief at the time of giving birth to an illegitimate child, or when pregnant of such a child.

(Jones 1972:204-5)

These categories did not permit wholesale certification unless parents or guardians wanted it, and for adults it was quite difficult to obtain certification unless they fell into (i) to (iv). It was also necessary that the mental defect had been present from an early age. But it will be noted that pauper women with illegitimate children were targeted, as were people charged with offences. The Act therefore was a potentially useful weapon for clearing undesirables away.

Certification was to be by two medical practitioners, one of whom was to be specially appointed by the Local Authority for the work, though those who were neglected, abandoned, cruelly treated or without visible means of support were the duty of a magistrate to report to the Local Authority. The vigilance of the Board of Education was crucial to the operation of the Act. If they took the duty seriously in time all potential defectives would be reported. In practice they did not always do this. Even if they did in the early days of the Act's operation they were not necessarily deemed as 'subject to be dealt with' by the Local Authority.

A central authority, the Board of Control, was charged with overseeing and inspecting the activities of local authorities, certifying and regularly inspecting certified institutions, and providing 'special institutions' for defectives who were dangerous or violent, i.e. Rampton and Moss Side. All discharges from certification were to be approved by the Board of Control. this was a potent weapon and one they used to considerable effect.

Counties and County Boroughs were the local authority unit responsible for implementing the Act. Each area had to have a special Mental Deficiency Committee composed of council members, with co-opted specialists. Its duties were the ascertainment of defectives, provision and maintenance of suitable institutions, care of defectives in the community including those under guardianship orders and supervision of other cases.

In 1927 the Act was amended to include people who became mentally defective after birth but before the age of 18 (Stainton 1991:15).

#### *The Wood Committee 1924 -1929*

For a number of reasons, including manpower shortages in World War 1 and financial constraints of local authorities (Sutherland 1984) implementation of the



1913 Act was initially patchy. In Chapter 5 I show that Bedfordshire was much slower to implement the Act than Somerset, for example. The Board of Control published annual reports which ranked local authorities according to the number of defectives reported, ascertained and in institutional care. The 'best' were those with the highest ascertainment rates per 1,000 (Thomson 1992, Chapter 6).

Agitation to implement the Acts of 1913 and 1927 more energetically led to the appointment of the Wood Committee in 1924, whose brief was to survey provision and numbers (Stainton 1992:18). The Committee discovered that there were 72,000 'unascertained defectives' (Sutherland 1984), and that the problem of feeble mindedness was growing (Thomson 1992:180). The Committee recommended:

- \* more use of 'community care' options laid down in the 1913 Act, i.e. guardianship, licensing, voluntary visiting of defectives in their homes
- \* the establishment of colonies by all local authorities which should provide for particular classes of defectives. These were to be large enough to be economical; a minimum size of 460 persons for each colony.
- \* that efforts be made to render defectives 'useful in the community'

(HMSO 1929, Alaszewski 1986, Stainton 1992, Thomson 1992.).

The Wood Report was clearly influenced by the eugenic beliefs that had inspired support for the 1913 Act. The decade following its publication saw a steady increase in institutionalisation, reaching 46,054 in 1939, by which date all but five local authorities in England and Wales had established their own institution (Board of Control Annual Report 1939). Bedfordshire had its own colony by this date, and, as I show in Chapter 5, the numbers institutionalised had begun to increase significantly in the late 1930s.

### *Sterilisation*

The segregationist solution to the 'problem' of mental deficiency was not the only one canvassed. The belief that mental defect was inherited was implicit in the Wood Report, though no concrete evidence could be produced (MacNicol 1987). The Eugenics Society was, according to MacNicol, behind the appointment of the Brock Committee which recommended the legalisation of voluntary sterilisation in 1934. This solution was energetically canvassed by a number of organisations, including some Local Authorities. I described in Chapter 5 how Bedfordshire was canvassed for support by Southampton in 1938, and refused to give it. Stainton (1991) argues that a number of interest groups were opposed to voluntary sterilisation, including the Asylum Workers' Union and the Catholic Church, but that the final demise of the sterilisation lobby was due to the excesses of Hitler's Final Solution; yet sterilisation of women with learning difficulties still commands widespread support, as is evidenced by the Janette case (Jenkins 1989).

### *The National Health Service Act 1946*

Responsibility for mental deficiency institutions, as they were still termed, passed to the NHS in 1946. It is hard to disagree with Stainton's view that it meant little change: 'The post war sense of collective responsibility had little positive impact on people with a mental handicap' (1992a:20). Responsibility for colonies passed to Regional Hospital Boards, severing local authority control. They were run on an explicitly medical regime, and any vestiges of pedagogical purposes vanished (Ryan 1987).

Local Authorities remained in charge of community care. Their duties included the prevention, care and after care of patients i.e. the provision of occupation centres and hostels, but this section of the Act was permissive, and Jones notes there was

great variation geographically (1972:277). As I showed in Chapter 5 Occupation Centres were created in Bedfordshire in the late 1940s, but the first hostel was not established until 1971. Mental Welfare Officers replaced the voluntary visitors of the pre war era, and Mental Deficiency Committees were replaced by Mental Health Committees. Professionals ousted the voluntary organisations. Technically Mental Welfare Officers were supposed to visit people under supervision quarterly, though the Bedfordshire evidence suggests that this was in practice less frequent.

Post War Welfare State reforms affected the family's financial responsibilities for their sons and daughters. Whereas families had had to contribute according to their means to the costs of keeping people in institutions, the inception of the NHS meant institutional care was free. National Assistance was available to people who qualified under the means test, meaning most Local Authority's discretionary payments to families of mental defectives in need ceased - though there was still provision made for those under formal guardianship.

The 1944 Education Act made it the duty of the Local Education Authority to report to the Mental Deficiency Authority any child over the age of two 'suffering from a disability of mind of such nature or to such an extent as to make him incapable of receiving education at school' (Hurt 1988:172). Children who were thus labelled were known as Educationally Sub Normal (Hurt 1988:172); though the Act permitted the inclusion of such children in mainstream schools, the pre war special school system remained basically unchanged, and LEAs could still exclude children deemed ineducable altogether (Hurt 1988:180). A number of the people I interviewed - Lynne, Barry, Jacqueline - had been excluded from school in the fifties.

## **1954 Royal Commission, and 1959 Mental Health Act**

The National Council for Civil Liberties provided the first major challenge to the workings of the 1913 Act on humanitarian grounds. Evidence to its national Conference in 1951 led to the publication of the pamphlet *50,000 Outside the Law*, highlighting the often arbitrary workings of the Act, and the affront to civil liberties it represented.

The 1954 Royal Commission was appointed to 'inquire, as regards England and Wales, into the existing law and administrative machinery governing the certification, detention, care, absence on trial or licence, discharge and supervision of persons who are or are alleged to be suffering from mental illness or defect, other than Broadmoor Patients' (quoted in Jones 1972:304). Jones suggests that the context was 'shortage of beds, shortage of buildings, shortage of staff and shortage of money' (1972:290), and quotes from a speech by Kenneth Robinson MP which refers to 'intolerable strain' and 'untold misery' suffered by families where there is a 'low grade defective' for whom no provision is made (ibid: 290).

The Commission heard evidence from numerous sources, including the Board of Control and British Psychological Society, which suggested that large numbers of people of 'dull normal and normal intellect were certified as mentally defective and compulsorily detained' (Clarke and Clarke 1978:25) due to the wide latitude given to practitioners to certify people who were anti social. There was also concern at the large numbers of people (approx. 6000) on hospital waiting lists and the slow growth in Occupation Centres (from 100 in 1948 to 312 in 1957) which meant an estimated 8000 people were without daytime occupation (Donges 1982:42).

The Act followed the main recommendations of the Royal Commission. Jones quotes the Minister of Health, Derek Walker-Smith as saying 'One of the main

principles we are seeking to pursue is the re-orientation of the mental health services away from institutional care towards care in the community' (Jones 1972:307). The Act abolished the old classifications (idiot, imbecile, feeble minded) and replaced them with 'subnormality' and 'severe subnormality'. The Board of Control was dissolved, and its powers of inspection and review transferred to local Mental Health tribunals. Most patients were to be admitted to hospital voluntarily and the power to detain was limited to specific conditions requiring treatment or observation where the detention was necessary in his interests or for the protection of others.

(all above from Jones 1972, Chapter 12).

Although the Act overhauled the legal and administrative machinery of the Mental Health Services the reorientation to community care was initially minimal. The Hospital population continued to grow to a peak in the late sixties (Stainton 1992a), whilst the development of Local Authority services was patchy. In 1962 four Local Authorities had no Occupation Centres; and in 1976 40 Local Authorities had no hostel places for adults (Donges 1982:65). Judging by these figures, Bedfordshire was by no means a backward Local Authority as its Occupation Centres date from the late 1940s, and hostels for adults from the early 1970s.

### *The Hospital Scandals and the Shift to Hospital closures*

Whilst the 1959 Act provided a framework for change, the impetus to deinstitutionalisation was lacking until the late 1960s. Jones attributes a changing ideological climate to several factors: the influence of Goffman's *Asylums* (1961); the spate of widely reported scandals in hospitals in the period 1968-70 which prompted revelations of cruelty, overcrowding and understaffing; and the publication of the 1971 White Paper *Better Services for the Mentally Handicapped*.

This was described by a contemporary as 'the great guiding light of our time' (McCormack 1979:15)

The White Paper 'set out the principles, philosophy and priorities for an improved service for mentally handicapped people based firmly on the principles of community care.' (Dalley 1989:199) and stressed the importance of people living with their families or, failing that, in 'home like' surroundings (HMSO 1971). It was intended that a six-fold increase in local authority residential places was required, accompanied by a drop of 50% in hospital places (Booth, Simons and Booth 1990:2). The pace of change was slow, due in part to financial constraints. Money accrued from running down and closing hospitals went to Health Authorities, whilst Local Authorities were responsible for providing community residential facilities (Booth, Simons and Booth 1990).

The 1970s saw relatively little progress towards the Government's stated aims of reducing the hospital population. (Wright, Haycox and Leedham 1994). Stainton calls this 'Big Talk, Small Steps' (1992b) though the decade was punctuated by initiatives demonstrating good intent. For example, in 1975 Barbara Castle, then Secretary of State for Social Services, acknowledged the slow rate of progress, and as a sign of commitment to change set up the National Development Group to advise on development and implementation of policy (Booth, Simons and Booth 1990).

The White Paper of 1971 lacked any clear conception of community care, being more concerned with closing hospitals than creating positive alternatives (Stainton 1992b). The Jay Report published by the Committee of Enquiry into Mental Handicap Nursing and Care enshrined in its principles the rights and individuality of people with learning difficulties and heralded the Ordinary Life movement (Kings Fund 1981) based firmly on the principles of normalisation (Emerson 1992).

Alaszewski and Ong regard the Jay Committee's views as the first official manifestation of a move away from community care as the provision of purpose built hostels on the edges of towns (hostels like Wauluds in Luton) to the provision of ordinary houses as homes for adults with learning difficulties (1991:27).

The 1980s saw distinct progress in terms of reducing hospital populations. Wright, Haycox and Leedham write 'Since 1981 there has been a steady progress towards the replacement of hospital by residential care' (1994:33). Between 1980 and 1990 there was a 37% decrease in NHS beds, a 40% increase in places in local authority residential homes: but by far the greatest increase was in places in voluntary sector and private homes, 271% and 546% respectively (ibid:33). This new mixed economy they regard as a product of ideological shifts (HMSO 1989) and finance through social security payments which supplement the resources of health and local authorities. In some ways it is a return to the pre World War 2 mixed economy in which care was provided by a mixture of family, local authority colonies, voluntary institutions and private homes (see Chapter 5), though the ideology is significantly different. The influence of the shift to a mixed economy in the 1980s and early 1990s was evident in the research. Interviewees lived in a variety of accommodation, some Local Authority, some Health Service, some provided by Voluntary Organisations, and some privately owned and run. Furthermore, the pace of change was accelerating with Isobel leaving the Local Authority run hostel to live in a voluntary sector group home during the period of the fieldwork, and Jacqueline moving into a privately run home shortly after the fieldwork was completed.

Influenced by the Jay Report, the National Development Group and the Campaign for Mentally Handicapped people (CMH), normalisation became the underpinning philosophy of new residential services. PASS and PASSING were influential

training tools primarily for professionals who were thereby encouraged to evaluate the services in which they worked in an explicitly normalisation framework (Lindley and Wainwright 1992), and research was similarly influenced by Wolfensberger's principles for combating deviancy-creating services (Chappell forthcoming).

### *Changing Day Services*

In many respects developments in day services lagged behind developments in residential services. Only in 1991 did the Department of Health instruct Local Authorities to 'plan to shift away from services based on the traditional Adult training Centre' (HMSO 1991 Para 15). Services should be based on an assessment of individual needs using ordinary community facilities (Wright, Haycox and Leedham 1994). As Chapter 5 showed, Local Authorities including Bedfordshire had begun in the 1980s to abandon contract work in ATCs in favour of a recreational and educational function for those institutions. However, the 1991 Circular urged further changes in role for ATCs, so that they become 'Resource Centres' to facilitate the use of ordinary community facilities - colleges, shops, cinemas, clubs and the like. In Chapter 5 I discussed the changing roles of Day Services in Bedfordshire, and pointed out that initiatives like Project Redpact did have the explicit aim of stimulating the use of community facilities for selected ex hospital residents, like Arthur, but that the traditional ATC provided the bulk of 'day care', particularly for those people living at home with parents. The dangers of a two tier service with priority being given to people leaving hospital had been noted by the Audit Commission (1989), and the evidence from this research is that this fear was not unfounded.



### *National Health Service and Community Care Act 1990*

Although this Act was passed in 1990, its implementation was delayed until 1993 (Wright Haycox and Leedham 1994), and therefore its impact is technically beyond the scope of this research. There was no discernible impact on the lives of the interviewees, not surprisingly, as the research took place in 1991-2. No one had a care manager; or if they did did not mention it. There was no evidence that services were becoming user led, or indeed carer led. If individualised packages of care were in operation, the recipients of such care made no reference to them, other than the occasional failure to keep promises of employment (Denise and Arthur).

### *Users Movements*

Two distinct user movements have emerged in learning disability since the Second World War. Chronologically the first of these, the mobilisation of the voice of parents and families, made its appearance in 1946 when the Association of Parents of Backward Children was formed (Stainton 1992a). Expansion was rapid, with the Luton branch becoming established in 1955 (see Chapter 5). The Association was sufficiently recognised to be asked to give evidence to the 1954 Royal Commission. Its position is characterised by Stainton (1992a) as cautious, with a call for more support in the home, without a rejection of hospitals as such. This Association, now MENCAP, has been the more influential of the two user movements as far as policy is concerned. Members of MENCAP are frequently represented on local Joint Consultative Committees and are the most likely pressure group to be consulted at both national and local levels (Mencap 1994). The local evidence suggests that Rene Harris, a prominent MENCAP activist since 1955, overstated their influence whilst Cecil French tended to dismiss the importance of parents' views in influencing policy (see Chapter 5).

Self Advocacy, the voice of people with learning difficulties, is a more recent development, with People First of London and Thames, the largest and oldest of the People First branches in England, celebrating its 10th anniversary in 1994 (People First Newsletter Sept. 1994). Its national coverage is patchy. In Luton the Speaking Up group referred to in this research has been affiliated to People First nationally; however, as the research shows, awareness of self advocacy is not widespread, and the one person who was involved in local policy forums, Brian, shared his platform with parents in the User Forum. People First do have representation on some national groups, such as the National Carers Forum, but complain that theirs is one small voice amongst many (personal communication).

## **Conclusion**

This overview of developments in learning disability in the twentieth century is of necessity brief. I have tried where possible to make links with the locally based research, and demonstrated that many of the trends in national policy described here are consistent with the findings of this research. To conclude it is apt to quote from Tim Stainton's final paragraph in the series of articles recently published in Community Living which represent the most trenchant and comprehensive analysis currently available:

*While rights and choice are the emerging rhetoric, control and paternalism, albeit more benevolent, remains the norm which current reforms are failing to challenge. (Stainton 1992b:17).*

## Appendix 5

### Extracts from Interview Transcripts Relating to Chapter 7

**Interview with Beryl held on October 1st 1991 at 7 pm**

*In this extract from my interview with Beryl, I have chosen to illustrate the way Beryl commented on the lives of her contemporaries at the Centre, including her friend Eileen who was present at the interview. The interview took place in Beryl's flat.*

Jan: Cos I wondered if you'd ever thought of getting a job in a playgroup, or old peoples' home or anything like that.

Eileen: Jan, no I hadn't I'd love to. I love children.

Beryl: That what Jane do next door.

Jan: So you'd like to do that sort of thing, would you?

Eileen: Wouldn't mind it.

Beryl: It isn't easy, Jane found that out. When they're naughty one of the teachers came down on her, didn't she?

Jan: When one of the children is naughty Jane got ticked off.

Beryl: Yeah, cos they say something to one helper, one of the other helpers ticked her off.

Jan: Well, that's always a problem with jobs, though, isn't it?

Where does Jane work?

Beryl: In the playgroup over 'ere, Wednesday morning.

Jan: So Jane goes to help?

Beryl: Yeah, yeah.

Jan: So she goes to Bramingham other times.

Beryl: Yeah, yeah.

Eileen: I'm happy there.

Jan: You're happy at Bramingham are you?

Eileen: Yeah.

Jan: Oh good. Have you ever thought of leaving it?

Eileen: I might be going in Beryl's area.

Jan: Carol said you ought to move.

Eileen: Yeah, down Beryl's area.

Jan: Is it better down there?

Beryl: Cos it's for more higher up ability people. She with the low ability people.

Jan: Yeah, what's it like being with the low ability people.

Eileen: All right. I don't mind.

Beryl: It don't help her though. She pulled backwards, see, with the low ability people, people who are a little bit

Jan: Is that right, Eileen?

Eileen: Yeah.

Jan: What do you think about that? Do you think you'd get on better if you were in the higher group?

Eileen: Yeah.

Beryl: See. 'fore she had her accident she were in the higher ability area.

Eileen: Yeah, that's where I had my accident.

Jan: What were you doing then?

Eileen: I was working. Now, what was I doing? Come on, get your brain working, Eileen. Hinges. Fixing hinges. Crackers. Christmas crackers.

Jan: More complicated than boxes.

Eileen: Yeah, yeah.

Beryl: See when she had her accident they brought her back to the low ability area.

Eileen: I fell over and broke my leg.

Jan: And then they brought you back to the low ability area? Were you sad about that?

Eileen: Not really, I wasn't very happy there.

Beryl: Anyway, it were too far for her sister to come.

Jan: Does your sister come to Bramingham then?

Eileen: Yeah, with Dr. Itmah's meetings, she comes then.

Jan: What are they about, these meetings?

Eileen: About how I'm getting on and that. I'm on tablets.

Jan: You told me you were having crying fits.

Eileen: Yes.

Jan: You told Beryl about that?

Eileen: yeah, she knows I cry, don't you?

Beryl: Yes.

Jan: You don't know what it's about. [Silence]. Sometimes you seem really lively and happy.

Beryl: Then other times, right down in the dumps.

Jan: Yeah, do you have that or are you even tempered, Beryl?

Beryl: Very even tempered.

Jan: Yeah, I thought you were. I asked Eileen when we were doing this what she thought was the happiest time of her life.

Eileen: When mum died.

Jan: Now, that was the saddest time when your mum died.

Eileen: Saddest time. Happiest time, what was that?

Jan: You said it was your holiday.

Eileen: Holiday, yeah. That was the saddest time, when mum died.

Jan: I think you were down in the dumps when I saw you the second time. A bit depressed.

Eileen: Yeah, I often get like that.

Jan: What about you, Beryl, what's your happiest time?

Beryl: Can't remember a happy time, really.

Jan: You don't know. Difficult question, isn't it?

What about sad times? Does that stand out?

Beryl: Not really. [Silence].

Jan: Cos Eileen said the saddest time was when her mum died. Was that very sad for you, that time?

Beryl: Yeah. I knew it were coming.

Jan: You were ready for it. But I suppose you must have felt sad as you'd been looking after her.

Beryl: Yes.

Jan: Deaths are difficult. Did you know about your mum dying, or did it happen suddenly?

Eileen: My mum was very ill. Cancer.

Jan: You did know she was dying. You were quite young then, weren't you.

Eileen: 16.

Jan: You weren't as young as that, Beryl.

Beryl: 34.

Jan: 34. I don't need to do the sums. You were quite young cos my mum and dad are both alive, and I'm 41.

Beryl: Yeah. Me brother were only 54 when he died.

Jan: Yeah, there's no telling, is there? I'm aware you are missing East Enders. Do you want to watch it?

Eileen: We can see it Sunday.

Jan: Are you sure?

Beryl: Yeah, we don't mind missing it for once.

Jan: Oh that's nice of you. What else did we talk about, Eileen? We talked about boyfriends, didn't we.

What about you, Beryl, have you had any boyfriends?

Beryl: No, don't want one.

Jan: Cos you, Eileen said you had one, but you don't meet him often now.

Eileen: No.

Jan: What's it like at the Centre are there lots of boyfriends and girlfriends there?

Beryl: They stop it a little bit. One girl, going out with Gary Parsons, he went to Silsoe, so she lost her boyfriend, they sent him away. He gone this week.

Jan: They started back at Silsoe this week.



Beryl: Some come back, some have gone. They do two years, then they come back, then more go.

Jan: Mm. The other thing I asked Eileen which she found difficult to answer was what she was looking forward to. You found that really difficult.

Eileen: If anything happens to my dad I think I'll be living with my sister, I think I will, not sure yet.

Jan: Have you spoken to her about it?

Eileen: Yeah, she said she'd have me, so.

Jan: Is that what you'd like?

Eileen: You'd rather that than live by yourself like Beryl, would you.

Eileen: Well, not unless a Group Home, or something like that.

Jan: You'd like to live in a Group Home, would you?

Eileen: Yeah.

Jan: Has anybody asked you? Have you got a social worker?

Eileen: John. John Butler.

Beryl: He often come in our workshop. You torment him, don't you? He her social worker as well. Did you know that?

Eileen: Is it ?

Jan: Have you spoken to him about what would happen?

Eileen: No.

Jan: Would you want to?

[Silence]

Eileen: Don't like to upset me sister, but ..

Jan: What do you think? I think it's important sometimes to think what you want yourself. What do you think, Beryl?

Beryl: She would be happy with people her own age group, yeah.

Jan: Might be nice to be in a Group Home.

Beryl: Mixing with some more. She'd be very isolated up there with her sister. her sister works. Two boys won't be there for ever. She be stuck up there.

Jan: Except you'd still go to Bramingham, would you?

Eileen: Yeah.

Jan: But you wouldn't be able to get over here very easily, would you?

Eileen: Yeah.

Beryl: I used to live up that part. I go up there to me neighbours and that, don't I, Eileen.

Eileen: Yes.

Jan: I think you should think carefully about that.

Eileen: I'll have a think about it.

Jan: You have a think about it. Are you good at saying what you want?

Eileen: No.

Jan: Are you Beryl?

Beryl: Yeah, I been brought up with a mind of me own.

*We continued to discuss how parents differ in their attitudes to independence in their sons and daughters.*

## Second interview with Bert October 15th 1992

*The interview took place in the day room on Bert's ward at Bromham Hospital. This extract illustrates the way Bert responded to my checking his 'Life Map' with him.*

Jan: I did this thing which is trying to make sense of what you told me. You'll find it hard to read, I know. Do you want me to read it to you?

Bert: You can do, yeah.

Jan: I tried to put the events of your life in the order they happened. And you were very good at it, very clear.

Bert: Oh yeah.

Jan: So I've got you down as born in 1937.

Bert: Yes, I was born in 1937, 1st September.

Jan: Ah. I haven't got that.

Bert: I was a little boy when the war was on though.

Jan: Mm. Do you remember it?

Bert: No, I was little. Me mum used to go, I used to run over the shelters, I remember the shelters though.

Jan: Yes.

Bert: Sirens used to go, we used to get in the shelter.

Jan: Anyway, you lived in Newton Street.

Bert: Yeah, I was born there, I was born in Newton Street, wasn't born in hospital.  
Cos Diana Dors used to own the Parrot.

Jan: Yeah, I've got that. And you had two brothers and two sisters.

Bert: Yeah, I had two but one died of cancer. She used to live near Dennis, Barbara.  
She died of cancer, smoking. I had two sisters.

Jan: One's in America.

Bert: One's in America, and one used to live in Luton, but she died of a heart  
attack, smoking, and she had Steven, he was feet first, it should be head first  
shouldn't it, he had irons on his legs, you know, Steven, but he recovered though.  
And when she died and her husband died, and she left him the council house, he  
had the council house.

Jan: Steven.

Bert: Yeah.

Jan: And you told me outside you were the middle brother. Don's the oldest.

Bert: I think Don is the oldest.

Jan: And Dave is the youngest.

Bert: David's the youngest, he's been married three times, David.

Jan: And your sisters?

Bert: In America.

Jan: I just wondered if they were younger than you or older.

Bert: She had a good married life, Louie, she married a good American. She brought me a hat back from Alabama, American Hat, Alabama hat, and the year before she sent me a buckle. {*shows me*}

Jan: Oh that's nice.

Bert: An Alabama one.

I haven't been over though.

Jan: You ought to go.

Bert: That's what Don says, go over and see her. She's married a nice husband though, she was engaged to an English bloke but he blacked her eyes so she packed him in. Cos she did two years in the army, Caterers corps, he was an English bloke, she went out with, then she met a nice American. I was at the wedding you know. She been in the States about 30 years now, she had a good wedding. When she was single she used to work at AC Delcos you know in Dunstable, doing ball bearings for cars you know. She coulda gone in the films you know she had talent for it. She had judo lessons. She put me on me back.

Jan: Did she?

Bert: Yeah, she threw me over her shoulder, she's only little but she can handle herself, yeah.

Jan: You showed me a picture of her last time.

Bert: Her and her husband, that's right.

Jan: Anyway, then I've got you went to school when you were 6, you said.

Bert: Yeah, it was supposed to be 5 but I wouldn't learn so they sent me to a backward school. Don said you still could have learnt though if you went to school at 6.

Jan: Mm. I've said here 'I never used to go. I didn't like school'.

Bert: I didn't like school, I didn't like school. I couldn't read at all when I left school, I went to become a plumber though cos I done 3 years of it and my guvnor said I don't think he will so I never passed and then I went to work on the buildings.

Hod carrier.

Jan: Oh you were a hod carrier were you?

Bert: Hod carrier, that's my trade. Hod carrier. Outdoor work, yeah. Pushing the barrows, cleaning the vans, yeah.

Jan: So you were a hod carrier. And then I've got you left school age 16, and you got work as a plumber for 3 years. Then I've got you were out of work for a while, but you weren't you went to work on the buildings after that, and then you were out of work.

Bert: Then I was on the dole and I didn't pass entry for National Service, so I went to see if I could join the Regular Army and I passed me intelligence test, I was grade 3.

Jan: But you were discharged cos of your feet.

Bert: Me feet, awful feet they bleed. I ain't supposed to wear boots they gave me foot powder. I done well in the army though, that's what the sergeant said, and I was doing the marching and all me toes they were bleeding they said I got to come

out. They put me in the kitchen. I like cooking, I can cook a bit, they put me in the kitchen till me discharge come through.

Jan: And then it was after that that you got into trouble was it?

Bert: With the law, yeah, then I went to Leavesden first, and I kept outa trouble on parole, then I went home, they discharged me cos I kept outa trouble , and I got in trouble again they said we can't send you to Leavesden cos you absconded , I broke the law, they sent me to Magull.

Jan: Mm. So that was when it all went wrong really, yeah.

Bert: Yeah, I shoul'da learnt reading at school but I couldn't concentrate. All my mates was brainy, they did National Service, all my mates that was at school with me.

Jan: So you regret it now do you?

Bert: Yeah I do, I regret it for a trade, yeah.

Jan: So you went to Magull for six years and you said you worked in the book shop. Is that right?

Bert: Bookshop?

Jan: Boot shop.

Bert: Yeah at Magull. A State Institution. State. Like a prison it was, high walls you know, and I worked in the boot shop for a while, didn't like it, making me bad, then I see Dr. Webster, I said can I go in the gardens, he said yeah, they put me on the gardens, and I worked on the gardens ever since till they send me to 'ere.

Jan: So you liked the gardens better?



Bert: Yeah, I like outdoor work you know.

Jan: Yes. Right so the bookshop is wrong. You came out after six years but your mum was dead, you just spoke about that.

Bert: Me mum died while I was at Magull, see.

Jan: So you were sent here.

Bert: Sent here, yeah.

Jan: Before your feet touched the ground. Did they just send you from there to here? Did you go home first?

Bert: No I went from Magull to here. I've had 3 jobs since I been in Bromham, that's what Pam said you done well. I was in laundry 7 years you know but I went home from Passenham (*ward*), over there I was over there when I first come, yeah.

Jan: And you went home from there.

Bert: I went home and I worked at Legrave, packing curlers, I was with me youngest brother then, David, he was married once to his first wife and then I didn't like the job, I said Don, I said Dave I come back to Bromham, it didn't pay well £1 15 a week though, cos his wife used to cook me meals and I come back here and I worked in the TAC for 4 years then I come out the TAC and I got a job as a porter, I been doing it 8 years.

Jan: You were doing curlers in Legrave.

Bert: Yeah, it's in Legrave, it's a little training centre it is.

Jan: What, Bramingham?

Bert: Eh?

Jan: Bramingham Centre?

Bert: Yeah, in Leagrave. I used to go on a bus but sometimes you see I used to miss the coach. I didn't like it much. I didn't pay board or nothing. His wife used to cook me meals for me though. Yeah.

Jan: So then you came back to ..

Bert: I come back here and worked in the TAC for 4 years then I come here and work with Lawson for 8 years.

Jan: So, what's it, I mean I think I've got it all really. And then I've got that your name has been put forward to leave but it hasn't happened for some reason.

Leave here.

Bert: Leavesden?

Jan: No. Leave here. To go out of here.

Bert: Well I was going to Marsh Farm, I went there 2 months running. I liked it but ?? said it wouldn't suit you.

Jan: The hostel in Marsh Farm?

Bert: It's in Luton, yeah.

Jan: The hostel, Wauluds?

Bert: Went there 2 months running from here, I used to come back on me own and Ray used to take me there, I used to come back on the bus, and I went there 2 months running on a Tuesday, they give me £10 allowance if I'd have gone there

but the people in the Marsh Farm said it wouldn't suit you, and Maggie said you got a good job here.

Jan: Who's Maggie?

Bert: She was a nurse here. Few years ago I went to see her and ask her to come back, she said I like to come back for you, but I was sweet on Maggie, hair like Pauline but all ginger hair you know, all down her back. I went down to her flat. I did have a snack there, I left there about 10 past 6 though, yeah. She said I'd like to come but she is going to Greece. See nurses when they come ??? Briggs he's gone to Marsh Farm, he has, in an old peoples home. Gary's gone, Gary Jabson, he gone to Bedford somewhere.

Jan: So they are leaving, people are going.

Bert: This place will close down in 4 years time. They are making flats here I think.

Jan: Yeah I been told that too. People going from this ward as well?

Bert: Going to close down in 4 years time, yeah.

Jan: Is it funny being somewhere where people are leaving?

Bert: Yeah, yeah.

Jan: Well I think you've given me a very good picture Bert.

*Subsequently I replayed the tape of our first interview, at Bert's request.*

**Lynne, First Interview on Tuesday 18th June 1992 at 7.45 pm**

*This first interview with Lynne took place at Wauluds hostel. At Lynne's request her Work Placements Officer, Rita, was present. The extract I have selected illustrates how we jointly interviewed Lynne to discover the nature of the work she did caring for her father. It comes from the middle of the interview.*

Rita: So actually when it comes to dad we ought to look and see just how many people there are to care for dad. There's you. Come on, I can think of somebody.

Lynne: Me sister.

Rita: No, she lives in Yorkshire. Who comes to visit your dad?

Lynne: Home Help.

Rita: Anybody else?

Lynne: Home carer.

Rita: Home carer? I don't know about those people. You tell me what they do. I don't know. I'd like you to tell me.

Lynne: She gets his breakfast and washes up.

Rita: Can I ask, does she get him out of bed as well?

Lynne: He gets up on his own.

Rita: He gets up on his own. Does he wash himself?

Lynne: No.

Rita: Not even his face and hands?

Lynne: No.

Rita: He's got a motorised wheelchair. Why can't he do that? Do his arms work?

Lynne: One arm does.

Rita: Ah, so he's got one arm that doesn't. What's wrong with that one?

Lynne: Well, he fell a couple of years ago. I was at work.

Rita: So he can't actually wash himself. He's got one arm. Does it move at all, or..?

Lynne: No.

Rita: Can he move his fingers?

Lynne: He can move his fingers a bit. He's blind.

Jan: Blind as well?

Rita: Not totally blind.

Lynne: He's nearly blind.

Rita: He's nearly blind as well.

Lynne: He can't see.

Rita: Poor dad.

Jan: That's the diabetes I suppose.

Rita: Yes, it would be, of course. Do you know how old dad is?

Lynne: 67. I think. 67.

Jan: Quite young, isn't it, to have all that?

Rita: You sure he's 67?

Lynne: Mm. I think he'll be 68 this year.

Jan: So he has a home help, home cares. Anyone else?

Lynne: Nurse comes.

Rita: Every day these people come?

Lynne: Sometimes the nurse comes, not every day.

Jan: And you. And Edwin. Quite a lot, isn't it really. From what you say it sounds as if it would be hard to manage without you here.

Lynne: Mm.

Rita: I'm still trying to paint this picture in my mind. You've got all these people coming in in the day time, but what about you, you get up to go to work. What time do you get up?

Lynne: When the clock goes at 25 past 5.

Rita: Lynne, you make me feel so tired. As early as that, 25 past 5.

Lynne: So I don't have to rush around.

Rita: Who sets the clock?

Lynne: I do.

Rita: Although you can't read or write you are very good at the time.

Lynne: I can tell the time and I know the date.

Jan: You know when people are late.

Rita: And do you do anything for dad before you go to work?

Lynne: He's in bed.

Rita: So you are free of looking after dad in the mornings. You look after yourself and you toddle off to work. Yeah. That's right. So the first time you have anything to do with dad is after work. Do you go straight home?

Lynne: Thursday nights I go down to pay me rent. I got to pay me poll tax this week.

Rita: It's all go, isn't it?

Lynne: Mm

Rita: And then your dad's waiting for you to come home.

Lynne: I go in the Estate Agent's next door, too. I still pop in to say hello.

Jan: That's the place you used to get your wages.

Lynne: I still pop in to say hello if I'm passing.

Rita: Nice to keep friends isn't it. What do you do for dad when you get in.

Lynne: I wash up.

Rita: You wash up straight away?

Lynne: I put me slippers on first.

Rita: So would I. What about dinners then? Do you do dinner after you wash up?

Lynne: No I put me dinner in the oven to warm up.

Rita: Just yours?

Lynne: Yeah, cos he has his dinner at dinner time.

Rita: Oh, I see. And I suppose the home help puts the dinner in the oven. You did tell us that earlier, didn't you. You're painting this nice clear picture in my mind now. I can see it. So your dinner's on the plate and you put it in the oven and warm it up. I remember you telling me that some years ago cos I was worried about you, you warming it.

Lynne: Bacteria. It wasn't warm enough.

Rita: Your dinner's warming and you start washing up, do you. Where's your dad at that time?

Lynne: Watching the TV.

Rita: How can he look at TV?

Lynne: He listens to it.

Jan: Sits in front of it I suppose.

Lynne: Sometimes on top of it.

Rita: So you are washing up, your dinner's warming.

Lynne: Then I go to bed. When I've had a bath.



Rita: You do lots of things, then.

Jan: How does he get to bed?

Lynne: He's got one of those things.

Rita: He's got what, Lynne?

Lynne: Can't remember what you call it.

Jan: Is it a hoist?

Lynne: One of those things makes a funny noise.

Rita: Pulls himself into bed.

Lynne: Makes a lot of noise.

Jan: So your jobs are doing the shopping, paying the rent, that sort of thing. Electric bill, do you do that?

Lynne: The home help likes to do that. She goes down town more than I do.

Rita: Who chooses what you buy then?

Lynne: Dad writes a list out and we have to get what he wants. He likes his stew and dumplings and I don't.

Rita: Do you buy that ready made?

Lynne: It's in a packet.

Rita: In a packet. I expect you buy quite a few packets.

Lynne: Chicken in a packet. And shepherd's pie.

Rita: Actually, it's just occurred to me. If you can't read how do you know what to do. Tell me, tell me.

Lynne: I just put it in the saucepan, turn it down low, when the potatoes are done I know it's done.

Rita: Do you peel your own potatoes then?

Lynne: Saturday nights I peel the potatoes.

Rita: For the whole week? Gosh, this is really intriguing me.

Jan: Quite a picture isn't it really? You have to be very organised don't you?

Lynne: Specially Sundays when I catch the ten to nine bus.

Jan: Down to the Salvation Army.

*We continued talking about the Salvation Army. Further details of Lynne's responsibilities for her father emerged at other points in both interviews.*

## **First Interview with Alanna on Thursday May 7th 1992**

*The interview took place at Church Street Adult Education Centre where Alanna went for literacy classes. This extract, from the end of the interview, is when Alanna talked of her sexual history and her fear of men.*

Jan: You really sort of say you prefer to be with women than with men, men make you feel anxious.

Alanna: Yeah even coming here is difficult, most of the time me head is down on the pavement, I'm afraid to look up.

Jan: Getting here.

Alanna: Yeah, very shy still but I get by. I mean the man that works in the greengrocers, he doesn't make me shy, he asks me how I am and I ask him how is he, you know, it's like he's older, he's married and he's older than me, you know what I mean kind of thing.

Jan: Have you been harassed by men?

Alanna: I have had problems. I went out with a coloured bloke once, he didn't like it if I looked, he thought I was making up to somebody else when I wasn't, that kind of thing, you know, he just wanted me to be for him like, wasn't rape or anything like that, but mum didn't like me being with him, you see this is where I wandered away from home like to these kind of places on me own and that's how I got into trouble, a lot, um, I think I was at home now with me mum, I don't think it would happen like this if you know what I mean.

Jan: And which would you prefer? Would you rather have stayed with your mum?

Alanna: I don't think so, I don't think I would've enjoyed it, I mean when I was young and wanted to go out, I always wanted to go out, didn't have many friends to go out with, so mum only kind of took me to the pictures once or twice and you can't do very much if your mum is there with you kind of thing and as I said if I lived with her now I don't think I'd get very far.

Jan: No regrets.

Alanna: Oh no I don't regret what I did, I regret being with the coloured person because now I know it was wrong to be going out with a coloured man, and I fell pregnant with him and I had to have the child killed which I don't think I liked and I still don't like, I mean to kill a human being, just not right, um having John is you know nice cos I loved the person I had John with, there again mum or dad weren't too keen on him, something or other, he was bit jealous too, he thought that I was looking at other men which I wasn't and making love as I know the word now but I didn't know it then, we used to do it in different places and not always the right place and he was in a hurry the last time we did it, like he wanted me to have John and just go like, not be bothered any more.

Jan: He just disappeared?

Alanna: Yeah, didn't want me any more which I was kind of sad and crying me eyes out, I don't know what happened after that.

Jan: Perhaps you've said enough for today, do you think?

Alanna: Yes.

Jan: We'll sit here for a bit.

*Extract from my research diary*

*After I switched off the tape we discussed follow up. We agreed I'd write a story for her and meet her at Church Street to read it through. I'll ring her first. I asked if it had been OK. She said it was good to know she could say all those things, and that they were true. But her mum would murder her if she knew.*

*I wrote a note for H- (tutor) and we both signed it, to say thank you.*

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