

'HOME-MAKING':

NEGOTIATING THE 'MEANING OF HOME' IN A RESIDENTIAL HOME FOR PEOPLE WITH LEARNING DIFFICULTIES

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ABSTRACT

This research project explores the meaning and management of the concept of 'home' in a shared, staffed home for people with learning difficulties. Work on the sociology of home has pointed to the importance of issues such as family, privacy, autonomy, work, gender and self-identity in forming and impacting the meaning of home and these issues are considered in the 'unusual' context of a group home.

Using data from participant observation, I look at how understandings of home are managed and negotiated by staff and residents in a particular shared, staffed house. In the context of this home, such understandings are integrally linked to and influenced by notions of 'care', 'independence' and 'disability'. I argue that both staff and residents draw from conventional ideas of home in order to understand this 'unconventional' home and also discuss the ways in which residents are sometimes disempowered and disabled through these processes.

I conclude by asking how shared houses for people with learning difficulties might engage with issues about the meaning of home and ask whether it may be necessary to reframe and refine our understandings and expectations of 'home' in order to better accommodate the needs, rights and wishes of people with learning difficulties.

INTRODUCTION

QUESTIONS AND ANSWERS: A BACKGROUND TO THIS STUDY

All research is perhaps inseparable from the researcher's life-history, their emotions and their drive to make sense of their own world (e.g. Coffey, 1999; Ellis, 1995). This study is no exception. After several years of working in services for adults with learning difficulties I had been left with a sense of righteous indignation and a lot of unanswered questions. I saw people with learning difficulties receiving services and support that was often friendly, supportive and empowering but that was at times subtly disrespectful, frequently rigidly dogmatic and occasionally blatantly dehumanising. The reality of everyday services seemed far from the ostensible ideals of 'empowerment' and 'fostering independence'.

Researchers perhaps also write about what they themselves most need to read. I questioned my collusion in the provision of 'un-ideal' care, yet like other staff, I was constrained by the exigencies of daily work and efficiency and organisational culture, yet had a desire to 'do things differently', yet I could not see, or even imagine, how things might actually be done differently. Such concerns led me to a desire to understand more fully the processes of control, care, and service provision as they occur in everyday settings, and to look at the daily experiences of people with learning difficulties as they are shaped through interaction with support staff.

Working with people who lacked words also made me ask how individuals who were daily disenfranchised in a verbal society (Poland and Pederson, 1998) might ever find a voice in the wordy world of academia. It seemed that my focus on interactions, relationships and

everyday context might also answer this question, as I shall discuss in more detail in Chapter 3.

In retrospect I see that it was no coincidence that I chose to examine life through the lens of the home. After several years of moving, travelling and searching for my own home, I turned to look at the meaning of other peoples' lives through the meaning of the home. As I will show, home is intrinsic to our understanding of everyday life.

THE IMPORTANCE OF HOME FOR PEOPLE WITH AND WITHOUT LEARNING DIFFICULTIES

The meaning of home has been a topic of sociological discussion, and is central to all our lives. The experience of home for people with learning difficulties has been little examined, although there is great potential for such research to reveal much about the everyday lives of people with learning difficulties and the dynamics of support services at the 'front-line' (Twigg, 2000: 1). Research in an 'unconventional' home might also provide further illumination about 'the intangibles embedded in the very concept of "home" '(Ravetz, 1995: 81). On a practical level, understanding the daily dynamics in a home may also inform service providers and residents involved in jointly negotiating such a home.

In this study I shall explore some of these meanings in an ethnographic case study of a 'small-scale' shared, staffed house for people with learning difficulties in a Northern city.¹ A home where un-related residents receive formal care raises a number of interesting questions for understanding the meaning of home- the house may well lack those

¹ Many types of community-based housing exist (offering various degrees of staff support) they include: 'independent or supported living' (with intermittent staff support), 'Village and Intentional Communities' and for some individuals, long-stay hospitals (e.g. Valuing People, 2001). The focus here is on 'small-scale ordinary housing' (ibid.) where a small number of residents share a house and are provided with continuous staff support.

aspects considered essential to a 'home' such as privacy, intimacy, family, autonomy and informality. In Chapter 2 I will explore these issues in the meaning of home, and the possibilities for their application to a home for people with learning difficulties.

Conducting research in anyone's home is an unusual and potentially intrusive act. Research with people with learning difficulties also raises other particularly complex issues of power and ethics. Chapter 3 outlines some of the difficult issues of voice and methodology I have engaged with while generating the data presented in Chapters 4-6.

In Chapters 4-6, I focus on how both *staff and residents* create, manage, negotiate and understand what is a potentially contested space. Chapter 4 briefly outlines the setting and participants in the study and raises some issues about how this house is understood as a 'home'. The importance in particular, of 'the family' in understanding this home is explored in chapter 5. The readily available model of the 'family home' influences both staff and residents' understandings of this house. However, tensions inevitably arise when the 'family model' is applied to a non-family home. In Chapter 6, I examine how the 'family model' intersects with other issues intrinsic to the meaning of home, such as privacy, autonomy and control. I discuss how the management of home-space, time and boundaries around the home are often controlled by staff, and how this sometimes compromises the ideals of home as 'private', and as a place of self-determination and self-identity.

Chapter 7 draws together the preceding discussion, highlighting how power structures and considerations of 'disablement' are integral to this analysis, and how existing models of institutional care and family homes perhaps limit the way in which home is understood in formal care, asking whether there are other metaphors for understanding homes for people with learning difficulties.

The general research question in this study is 'how is the concept of home understood and negotiated by residents with learning difficulties and staff in a group home?' Subsidiary research questions ask:

- 1) What does 'home' mean to residents and staff; what aspects of 'home' are most significant?
- 2) How is this particular home space understood, used and experienced by participants?
- 3) Are there conflicts or differences that arise from the various concepts of the idea and use of home?
- 4) How is the concept of home managed and negotiated in this house?
- 5) What is the interplay between these meanings and understandings of home and of broader social factors and power structures (e.g. gender, disability)?

DEFINING THE HOME

Home's centrality to human life means that it also impacts on many other spheres of everyday experience. However, constraints of space mean that there are therefore many aspects of home that I cannot fully investigate (see also Daly and Dienhart, 1998). For instance, although I do discuss the tension between the house as a place of work and a home, I cannot look in detail at *residents'* experiences of work-like activities at day centres outside the home. Likewise, although life histories offer an important lens through which to interpret social life, I cannot look in depth at individual's biographies and past experiences of home, although I have tried to incorporate them in understanding the texture of day-to-day interactions in the house. I also touch upon issues of gender in the home and the (gendered) nature of care-work, but again, such issues require more time and consideration than I have given to them.

In addressing staff-resident interaction and negotiation I am aware that I have eclipsed some of many relationships and deliberations which go on amongst residents, such as issues of space and of intimacy. Finally, in touching on issues of family life and 'conventional' homes I realise that such ideas are more multi-dimensional, subtle and complex than the stereotypical representation I may have given here, although I have sought to show how those simplified 'stereotypes' of home affect participants' understandings of this house.

I realise that I thus perhaps raise more questions than answers, and open up a number of avenues I cannot do justice to here. However, perhaps these short-comings reassert that 'home' is a complex, richly textured, infinitely variable and deeply layered part of human life which impacts, and is affected by, many spheres of experience and social interaction. As such, it is an essential and worthy field of study. In the next chapter, I will outline some of these themes in the meaning of home and explore their relation to homes for people with learning difficulties.

**‘WHEN IS A HOUSE A HOME?’:
THE MEANING OF HOME IN ‘CONVENTIONAL’ AND
‘UNCONVENTIONAL’ HOMES**

‘Home...is a central point of existence and individual identity from which you look out on the rest of the world. To build a new house... is a fundamental project, equivalent perhaps to a repetition of the founding of the world’

EDWARD RELPH

‘Place and Placelessness’, 1975: 83

OUTLINE

The social construction of space, place, and in particular the concept of ‘home’ has been the focus of much sociological interest. I will briefly define and discuss the concepts of ‘learning difficulties’ and ‘home’ before exploring how the sociological investigation of both fields has potential to intersect and to offer a deeper understanding of the everyday experience of home for people with learning difficulties.

LEARNING DIFFICULTIES

In contrast to the medical model of disability where disability is seen as an individual, internal characteristic, the social model of disability points to the fact that people with impairments are disabled by barriers in *society*. Such barriers limit peoples’ opportunities to partake in employment, to express choice over their living situations and the services they receive and often foster dependence on professional ‘help’ or services (e.g. Abberley, 1987/1997; Oliver, 1990; Barnes, 1990).

Researchers, professional 'carers', the lay public and more intangible entities such as organisations and governments help to create and perpetuate such disabling barriers.

'Learning difficulties' is a term used to refer to what may be considered 'intellectual impairment' (rather than physical impairment, although clearly the two may overlap).² People with learning difficulties similarly experience 'disabling barriers' in the form of attitudes, bureaucratic structures which foster dependence and inaccessible information (e.g. Aspis, 1999). Discussions of disability have, however, often neglected the fact that people with learning difficulties may not experience disability in the same way as those with physical impairments (Chappell, 1997). 'Impairment' for people with learning difficulties should perhaps also be seen in a social context, amongst the socio-political constructions of ideas such as normality, incompetence, and intelligence/IQ (Goodley, 2000: ch 3, Davis, 1997, Aspis, 1999, Jenkins, 1996).

A number of people with the label of learning difficulties also lack words. Unlike those disabled people who have recourse to language they have little recourse to challenge their oppression or to question society's dependence on and reverence for words and the powerlessness culturally associated with wordlessness (Poland and Pederson, 1998: 297). Research has attempted to include the usually

² Many service providers and government documents favour the term 'learning disabilities' (and formerly 'mental handicap') (for a discussion, see Jenkins, 1996: 7-9). Individuals with this label, however, often prefer the term 'learning difficulties' (e.g. see Goodley, 2000 :85).

'Difficulty' in learning is not unique to people assigned this label, for example people with visual or communicative impairments may also find learning a difficult process. The label rests on the assumption of an 'intellectual impairment', although it can be argued that such an impairment is difficult to define (Jenkins, 1996). Nevertheless, the people in this study had been given the label of having a 'learning difficulty/disability' and although I cannot examine the processes by which they came to acquire the label, I will endeavour to consider how that label is managed and perhaps reinforced in the context of everyday interactions with support staff, how it exists in a social environment.

'excluded voice' of people with learning difficulties in academic and professional discourse (e.g. Booth and Booth, 1996) but even research itself is singularly dependent on (academic and often impenetrable) words (Aspis, 1999). Moreover, such research frequently excludes those with more 'severe' learning difficulties who are less verbally 'articulate' than others (Walmsley, 1997: 63; Booth and Booth, 1996; Stalker, 1998; Goodley, 2000: 34). As I will show, there is potential for these issues to be explored with reference to the experience of 'home' for people with learning difficulties.

ISSUES IN THE MEANING OF HOME

A growing body of work has addressed the issue that 'the home environment not only designates a physical dwelling but also represents a *multitude of meanings*, such as personal identity, security and privacy' (Williams 2002: 142. Italics mine. For other summaries of 'the meaning of home' see e.g. Twigg, 2000: ch 4; Means and Smith, 1998: ch 7).³ This work on home offers many (as yet unexplored) points of intersection with consideration of the lives of people with learning difficulties.

i) FAMILY AND HOME

Family and home are inextricably linked. Bowlby writes that although 'non-family households also have homes, a crucial element of the everyday understanding of home is the notion of a place within which

³ Historically, from the 17th century onwards, 'home' as a term began to mean what we today understand by it. Rybczynski notes that it 'brought together the meanings of house and of household, of dwelling and of refuge, of ownership and of affection. "Home" meant the house but also everything that was in and around it, as well as the people, and the sense of satisfaction and contentment that all these conveyed' (Rybczynski, 1986: 62) It is interesting to note that the word 'home' itself, carrying this meaning of a metaphysical and emotional 'state' is specific to Germanic languages. Romance languages may attribute the same meanings to houses, but have no one word to express both the sentiment of security and relaxation *and* the physical place of home (ibid).

children are or will be reared' (1997: 344). Rybczynski concurs, noting that 'domesticity has to do with family, intimacy, and a devotion to the home' (1986: 75). Relationships with family members and their place in the home may change or be redefined over the life course (Mason, 1989), yet family remains key to the understanding of home.

Family is itself inextricably wrapped up with gender roles such as mother, father, husband and wife. Bowlby et al (1997) explore how the home is a site for 'doing gender', in that performing gendered tasks (e.g. cleaning, repairs) asserts and affirms gendered identities. However (particularly for women) those gendered identities may be perceived as limiting and constraining, and home then becomes a site for the exercise of power. For unpaid carers and home-makers (who are usually women), home may be a place of work and oppression (Williams, 2002; Bowlby et al, 1997; Gurney, 1997; Oakley, 1985; Swift, 1997, Finch, 1984) instead of the 'haven' from the outside world it is popularly understood to be (e.g. Bachelard, 1958/1994: ch 4).

ii) WORK

The notion of the home as a haven from work also means housewives may feel an obligation to maintain the identity of the house as a relaxed informal sanctuary for others, whilst simultaneously performing their (formal) tasks and work (Hunt, 1989). Similarly, home-offices present an ambiguous site that is confusingly both 'work' and 'home' (Marcus, 1997: 145 and ch 7). Paid domiciliary care also leads to complex negotiations about territory, control and the meaning of home (Twigg, 2000).

Work presents such tension in the home, because 'home' is itself defined by its diametrical opposition to 'work'. Work falls in the 'public' sphere along with formality and business while home is 'private', intimate, informal, relaxed and nurturing (Mason, 1989: 103).

iii) PRIVACY AND CONTROL

The distinction between the 'private' and the 'public', and correspondingly between 'insiders' and 'outsiders', is another key criteria in the meaning of home (Allan and Crow, 1989: 3-4, also Allan, 1989). Exercising control over the home symbolises that it is one's 'private' sphere (Allan and Crow, 1989: 8-9). Control may be over household routines or décor but also, crucially, over who is allowed to enter or see the home: as Allan and Crow write: 'A home of one's own is, then, valued as a place in which the members of a family can live in private, away from the scrutiny of others and exercise control over outsiders' involvement in domestic affairs' (1989: 4). The security and sense of refuge afforded by a home is somewhat dependent on this control over limiting access to 'outsiders' (e.g. Higgins, 1989: 172).

Defining the home as 'private', and exposing certain parts to public view is an ongoing negotiation (Allan, 1989). Such boundaries are not clear-cut: non-resident kin and close friends, for example, may inhabit blurry hinterlands between 'insiders' and 'outsiders'. As Mason (1989) points out, what is considered 'private' and 'public' by particular households is influenced by power dynamics affected by gender, family relationships and employment/retirement status throughout the life course.

iv) IDENTITY AND HOME

Security, privacy and control are intertwined with personal expression. The home may be a site for creative renewal through artistic endeavours when there is a sense of security of being in one's own territory (Swift, 1997). Marcus describes 'home' as 'a place of self-expression, a vessel of memories, a refuge from the outside world, a cocoon where we can feel nurtured and let down our guard' (1997: 2, see also Relph, 1975). The home may reflect and in turn shape the psyche, writers influenced

by Jungian psychology have asserted that the subconscious and the home often mirror one another (Bachelard, 1958/1994; Marcus, 1997). Well-being, quality of life and health are also promoted when an individual resides in a home which 'fits' well with his/her personal identity, producing a 'therapeutic landscape' (Williams, 2002).

Over time, identifying with a home means that history and autobiography become inextricably intertwined with place and objects in a home. Emotions, experiences and 'feelings occur in space and inevitably become associated with various highly charged places; feelings cannot occur "out of space"... Thus, any discussion of emotion and place must return to the observation that the two are inexplicably connected...' (Marcus, 1997: 245). Memories of events such as marriage, bereavement, having children and transitions into adulthood are therefore tied to the physical home (Gurney, 1997), while they also often trigger physical relocations or major conceptual redefinitions of home space (Mason, 1989). Home thus becomes linked to one's sense of self-history.

HOMES AND FORMAL CARE

Gurney remarks that 'women's voices have not been heard in accounts of home' (1997: 373). We might note however, that neither have the voices of *people with learning difficulties* been heard in such accounts. Few studies have addressed this area, despite the suggestion that 'there is hardly a better testing ground for examining the essential nature of 'home' and the power of the modern domestic ideal' (Higgins, 1989: 159) than 'unconventional' homes such as those provided for people with learning difficulties.

Research concerning formal residential care and the meaning of 'home' has focussed mainly on 'homes' for older people (e.g. Clough, 1981; Booth, 1985; Willcocks et al, 1987; Higgins, 1989) and on

institutional life for those suffering/diagnosed with mental distress (Goffman, 1961). These studies have emphasised the oppressive (often coercive) practises which rob residents of dignity, self-identity and autonomy, thereby highlighting the disparity between the conventional 'meaning of home' and the reality of daily life in these residential 'homes' and institutions. Residents may find that in contrast to their own home, the 'care home' environment fails to express or affirm their identity and past; affords them little privacy or 'territory', and limits their opportunity to develop intimate relationships which approximate kinship bonds (for example Willcocks et al, 1987: esp. ch.3; Higgins, 1989: 165-171; Clough, 1981: esp. 101-104; Goffman, 1961: 24-28). Higgins notes that the lack of such 'metaphysical' elements of home means that 'even when 'homes' are at their best, many residents find it difficult to regard them as their *real* homes' (1989: 171).

A good deal of research on homes for people with learning difficulties has emerged in tandem with the move from institutional living to community care. Many writers have emphasised the potential for independence in community-based small-scale housing (e.g. Cambridge et al, 1994; Fitton et al, 1995; Simons, 1998; JRF 1995b; Williams, 1995: 87). A number of researchers have also criticised the assumption that the move to small-scale housing *necessarily* affords independence, since residents often have no choice about who they live with, where they live, and lack control over household management (JRF, 1996 JRF 1999; JRF, 1995b; Ravetz with Turkington, 1995: 92; 1995b). Furthermore, although small-scale homes often purport to promote independence, services sometimes draw heavily from institutional assumptions and practises: 'for people with learning difficulties, 'too much communal accommodation remains institutional in philosophy' (Means and Smith, 1998:175).

The philosophy of community care, from the 1970s onward, was guided by a 'growing acceptance that those with disabilities of any kind, physical or mental, had a right to live as others lived, *in their own homes*' (Ravetz: 89. Italics mine). However, in contrast to the work on older peoples' homes, there has been very little engagement with the problem of what a 'home of one's own' actually means. Some studies assume that 'home' is un-problematically defined by length of residence. Cambridge et al for example, describe the situation of a service user who had remained in hospital for some time because alternative suitable housing could not be found: 'for Joan, her short-term emergency placement on a hospital ward appeared to have become a long-term solution. *It had become home*' (1994: 29, Italics mine). Several studies have asserted that tenure is an important factor in independent homes for people with learning difficulties (JRF 1996, 1999, Simons, 1998). For instance, Simons comments that 'while residential care may be provided in domestic scale settings, and it may be *home like*, it is not the residents' own home [if it is not owned or rented by the resident]' (Simons, 1998: 8).

However, while length of residence and tenure are important in understanding 'home', neither are sufficient to *fully* explain what 'home' *means* to people with (or without) learning difficulties. The issues raised by studies of conventional homes have not been applied to the meaning of home for people with learning difficulties. In summary then, studies of home for people with learning difficulties have largely failed to engage with the sociologically problematic and 'metaphysical' nature of home.

PEOPLE WITH LEARNING DIFFICULTIES AND THE MEANING OF HOME: SOME POSSIBILITIES

Those issues important to the meaning of conventional homes (outlined above) may intersect powerfully with the experience and lives

of people with learning difficulties in a number of ways. Although not all households are family units (Allan, 1989: 143-4) small-scale, shared homes present a particular challenge to the association between family and home. Small-scale homes generally house several unrelated and previously unacquainted adults (e.g. Fitton et al: 9). The majority of people with learning difficulties do live with their families, but move into a supported home after parents become ill or die (Valuing People, 2001: section 7.1; JRF, 1995b). Studies on homes for older people emphasise the loss of a prior home, possessions and (socially valued) identity, yet for people with learning difficulties the move to supported housing may signal the first establishment of a home of their own. Group homes therefore exist both in contrast to, and as a substitute and replacement for the norm of family-based living.

People with learning difficulties may have limited control over their homes (as I have shown above). In addition, there is potential for tension between residents' claim to *home* space which is also support staff's *work* space. Furthermore, it is unlikely to be perceived as a haven from paid work for its residents, since only 10% of people with learning difficulties are in paid employment (Valuing People, 2001). Issues of women's role and work within the home may also be highlighted by care in the home, since most support and care staff are female (e.g. Finch, 1984: 161).

Meanings of home and self-history may not be tied together as Gurney (1997) suggested for people who have learning difficulties, since they may lack those conventional 'milestones people use to order their past, such as ...setting up home, marriage, parenthood' (Booth and Booth, 1996: 57).

The small-scale home may thus present particular challenges and issues for the residents and staff as they negotiate the shared space, defining and framing it as a home.

Furthermore, housing for people with learning difficulties with more 'severe' needs and limited communication is most likely to be in a small-scale housing setting (Fitton et al, 1995: 2) rather than other 'independent living' settings (see footnote 1). It is precisely these individuals who, it is claimed, are marginalised in disability research when only the voices of more 'articulate' and 'independent' representatives with learning difficulties are heard. As the government transfers individuals with learning difficulties from hospitals to supported/staffed homes (Valuing People: 72)⁴ issues of what exactly home means in such a setting potentially has relevance for a growing number of people.

The seeming mundanity of home plays an intrinsic, defining role in the lives of people with and without learning difficulties: the business of domestic life fills many of our waking and sleeping hours, provides a base and a touchstone for other activities, and anchors, moulds and reflects our very 'selves' (Allan and Crow, 1989: 1; Twigg, 2000: 1, 4). However, for people with learning difficulties, home is also likely to be the site of the everyday care encounter. Any analysis of services for people with learning difficulties must acknowledge that 'it is at the front line that the true nature of care reveals itself. It is there that it is created; and only there can it be judged' (Twigg, 2000: 1). Examining how 'home' is created and managed at 'the front line' by both staff and residents (ibid.) provides a window into the daily experience and provision of support, an insight into the everyday negotiation of care provision: a representation of how 'disablement' might take place in the provision of services.

Given these issues, it would seem that the small-scale home is a fruitful site for study, impacting on many areas of concern to both the

⁴ The government intends all people currently in long-stay hospital care will move into 'more appropriate housing' by April 2004 (Valuing People: 72).

sociology of home *and* the quotidian experience of people with learning difficulties. I turn now to how these issues can be addressed, and how exactly the voices of people with learning difficulties may be heard.

CHAPTER 3

'BEHIND CLOSED DOORS'

ISSUES OF ETHICS AND VOICE IN PARTICIPANT OBSERVATION RESEARCH IN THE DOMESTIC SETTING

'Penetrating the veil of secrecy which surrounds home life in order to arrive at a balanced assessment of its nature and significance is no easy matter'

GRAHAM ALLAN AND GRAHAM CROW,
'Home and Family: Creating the Domestic Sphere', 1989: 1

OUTLINE

Methodological concerns in this study intersect with some of the issues of 'voice', 'disability' and 'disablement' I have outlined in chapter 2. In this chapter I will outline how I gained access to the setting, why I chose a reflexive, involved, ethnographic approach to data generation and how I have attempted to address some of the imbalances in power that are part of research and interaction with people with learning difficulties.

'LOOKING AT LIVES' : ACCESS, CONSENT AND PERMEABILITY

Home life is usually a 'fundamentally private affair, curtained off from the public gaze' (Allan and Crow, 1989: 1), and for sociologists an 'intriguing and frustrating mystery' (Hunt, 1989: 66; also Daly and Dienhart, 1998). Home life at number 42 was however, relatively open to my observation.

Cathy, the manager of the house had readily agreed to my visiting as a volunteer 'befriender' every week or two (over six months) and observing and participating in activities and outings. Volunteering offers a

somewhat non-partisan role since 'volunteers are in a good position to 'talk' to both users and staff' (Barnes, 1990: 43). The volunteer role also offers an opportunity to offer service in exchange for access (Lofland and Lofland, 1984: 40-1; Fetterman, 1989: 134-5), which I hoped would minimise the possibility of exploitation. In addition, justifying a sustained (and somewhat uninvited) presence in someone's home also requires adopting an acceptable or comprehensible role (Stalker, 1998: 9; Daly and Dienhart, 1998: 108). However, this did not alleviate all ethical dilemmas. Like Stalker (1998), I found that negotiating access to the home took place with managers rather than residents themselves and residents were not consulted about my visits until I had begun to volunteer.

Such managerial structures present problems for gaining 'informed consent' (BSA 2002: section 25) from people with learning difficulties. When participants also lack words, informed consent can be even more difficult to ascertain (Stalker, 1998). The best means of establishing an ongoing informed consent is perhaps developing a 'sense' of whether your presence and involvement in their lives is acceptable to them, a strategy I attempted to follow. However, this necessarily required getting to *know* residents, by spending substantial time with them (Darlington and Scott, 2002). Ironically, by then I had *already* gained access to their lives. Familiar staff may be able to facilitate communication and gauge whether individuals really want to continue to be part of the research. However, staff may not appreciate that such consent is even necessary.

Participants may forget or fail to understand the nature of 'being researched/observed' (ibid: section 29). This is as true for people with learning difficulties as those without. Staff's assumptions that my interest was necessarily in residents' lives posed an unexpected problem of consent, they perhaps did not fully understand that I was also observing *them* too.

Staff's assumptions of my focus also meant they often guided me to look at unusual aspects (e.g. of *residents'* behaviour and histories) and ignore what they perceived as mundane (daily interactions and staff activities). Some methodologists lament such biased 'barriers to data' generation (Lofland and Lofland, 1984: 36), implying that data exists independently, and needs only to be accessed. I have drawn from the alternative viewpoint that insights about what is important to participants can come from analysing 'what is profane and open to investigation vs. what is sacred and closed' (Barbera-Stein, 1979, cited in Hammersley and Atkinson, 1995: 55, see also Daly and Dienhart, 1998: 104). In particular, staff's assumptions of what I should want to see powerfully exposed norms and values within the home. Issues of access to the setting and information thus provided data in themselves,- it was exactly this type of nuanced and contextualised data I sought to answer the research questions.

AN ETHNOGRAPHIC, GROUNDED THEORY APPROACH

To address the questions about the meaning of home I took an 'ethnographic' approach (Mason, 2002: 84), although the intermittent visits and short length of my fieldwork means that this research is not strictly 'an ethnography' (Fetterman, 1989: 47). Following an ethnographic approach I undertook participant observation, conducted informal ethnographic interviews and considered documents (particularly with reference to how *participants* used and understood them in context). I did not separate 'formal interviews' from the interaction and participation I was involved in, as Atkinson et al write: 'conversations and interviews are often indistinguishable from other forms of interaction and dialogue in field research settings' (2001: 4-5, cited in Mason, 2002: 55). In part this was also because not all participants would have been equally 'articulate' in a formal interview setting, as I will discuss.

Understandings of home are produced in the daily regularity of interactions, practises and negotiations which participant observation is well-suited to investigate (Mason, 2002: 85). Taking a Symbolic Interactionist influenced stance, I looked particularly at 'naturalistic indicators': the 'symbols' which express participants' meanings and understandings, such as interactions, behaviours, accounts, conversations (Denzin, 1989: 94). My concern with contextualised behaviour meant that participants who did not use many/any words were represented equally alongside those who did. Formal, verbal interviews would have given only *verbal* participants an opportunity to express their views, whereas *all* participants were involved in activities such as using space, eating, and interacting in a combination of verbal and non-verbal ways.

Ethnography gives an opportunity to incorporate people with learning difficulties who 'lack words' (Booth and Booth, 1996). The qualitative interview method *can* be adapted to 'give voice' to people with learning difficulties, e.g. by broadening our comprehension of what it means to listen and acknowledging that 'silence may be as telling as talk' (Booth and Booth, 1996: 57). Nevertheless, an interview situation does not represent speech/silence quite as it occurs in 'everyday' *contexts* with familiar interlocutors. Poland and Pederson hint at the potential for ethnography to exploit this; 'the appeal of ethnography...is precisely its ability to generate insights about the context in which ...talk [and silence] take place and ... take shape' (1998: 303). How silence/words are used in *interactions* is one way in which I have found that people with few words can have a voice in representations of the field (Chapters 5 and 6). Ethnographic observation can thus provide an opportunity to 'hear'

the voices of people without words in a way that more formal interviews cannot.⁵

I drew also from a broadly 'grounded theory' approach (Strauss and Corbin, 1998), which emphasises generating data in interaction with developing theory and analysis. Observations shape developing theory and guide the researcher's gaze to further data, for example 'interviews acquire meaning from observations' (Hammersley and Atkinson, 1995: 117) and vice versa. This 'theoretical' sampling of data flows into analysis where 'open' and 'axial' coding is used to fracture the data and rebuild it into coherent theory (Strauss and Corbin, 1998). This research is a small-scale case study of one home, and as such aims to present a contextualised, nuanced, rich and full picture of the home (Blaikie, 2000: 213): essentially yielding an 'understanding' of the setting (Blaikie, 2000: 76-7). Ultimately however, Grounded Theory logic could also be used to test and extend my premises and theories in other similar and dissimilar homes.

In contrast to some ethnographers, I did not intend to remain a 'neutral' or 'detached' observer of 'naturally occurring' events (Lofland and Lofland, 1984: esp. 46; Denzin, 1989) or adopt the traditional Grounded Theory stance towards data as 'objective' where the researcher 'discovers' rather than *generates* theory (Strauss and Corbin, 1998: 45; 56). Even in relatively uncontrived settings, the researcher still defines and influences what is observed (e.g. Emerson et al, 1995: 167; Charmaz and Mitchell, 2001). My presence elicited

⁵ Ethnographic approaches *have* been used in research with people with learning difficulties (Edgerton, 1967; Angrosino, 1998), but these have focussed mostly on people with 'mild mental retardation' (sic) who use words. They have also failed to engage with issues of power or the social construction of disability and have focussed on *individuals* rather than the social context where disability exists. Edgerton's work, for example, dubiously promises an insight into 'the land of the retarded' (1967: preface).

data and reactions from staff who tried to 'make sense' of my role and anticipate what I wanted to know. Personal emotional reactions and auto-biography are also intimately related to what is seen and experienced (e.g. Ellis, 1995; Coffey, 1999). For example, as I noted following one visit,

Afterwards I felt oddly homesick, missing something that I saw there. My reading (and arrogance?) had lead me to assume that I was the privileged one, with independence and freedom people with learning difficulties would long for, that my entering then soon leaving would be traumatic- a manifestation of my 'power' to exploit them. However, I had spent the evening with them in their cosy living room, watching Coronation Street (where Richard Hillman returns to kidnap Gail and the children, an episode highly anticipated and enjoyed by some at the house!). And it was I who felt bereft on leaving, not them. Still relatively new to the city, living only with my husband and cat I longed for real 'family' life, of being drawn into the soap operas I didn't really like (but that my parents watched avidly), contracting the contagious excitement. The bustling of people on separate wavelengths, watching TV or playing music in their own rooms, instead of the quiet and mutual activities of my home. Perhaps what I was envious of was the thrill and stimulation of living with people I might never have *chosen* to live with. I thought that the lack of choice that residents had over their housemates and the staff who were a permanent part of their home automatically equated to disenfranchisement, powerlessness, even loneliness. Of course it may, but I was struck by the easy, familial and warm interactions amongst people thrown together by default, which for a little while made *me* feel lonely, (disenfranchised even) and nostalgic for a kind of 'home' I didn't have now.⁶

⁶ Emerson et al. (2001: 364) note that various strategies exist for incorporating fieldnotes into an analytic text. Commonly, explicit 'textual

Hammersley and Atkinson entreat ethnographers to 'strenuously avoid feeling at home' (1995:115) in order to retain a 'social and intellectual distance' (ibid: 102). Ironically, it was my quite literal sense of *not* being at home that brought home to me the inevitability of personal and emotional involvement in research. Emerson et al (2001: 361) note that recording emotional data may bring clarity to the feelings of both participants and of the researcher, and provide 'important analytic leads' (ibid). As the house triggered memories and comparisons of *my* other homes, so too did I come to see that residents and staff also contrasted, measured and modelled the house on *their* other homes. The home was dynamically moulded in the context of other families and homes, and any analysis of this house as a home had to examine this wider context.

POWER AND DIFFERENCE

Although I came to identify with participants' conceptual and emotional processes, standpoint researchers would point out that as a non-disabled researcher I could not fully appreciate the experience of people with learning difficulties. Issues of power in research are complex. In research such as this, the position of a non-disabled researcher presents a risk of exploitation (Stone and Priestley, 1996), One response to this inequity is to adopt an 'emancipatory' approach (e.g., Stone and Priestley, 1996). Emancipatory research has evolved from responses to exploitative research relationships and systematic exploitation of

offsetting' (ibid.) (visibly indented, italicised text) indicates a fieldnote excerpt. Such a strategy treats fieldnotes as external, objective sources of data, to be 'quoted'. Alternatively, the 'integrative strategy' merges analysis and experience together recognising that fieldnotes are continuously recreated and (re)presented. Since I have approached the fieldnotes as emergent, evolving sources of data, I have adopted the 'integrative strategy' here, *minimising* textual offsetting to indicate that fieldnote excerpts are not a 'pure' or 'external' source of data.

disabled people; to ignore this seems naïve, but there are also difficulties in adopting an explicitly 'emancipatory' stance. These considerations seem to conflict with Lofland and Lofland's claim that fieldwork is 'no more difficult ethically than everyday life' (1984: 43-4).

Firstly, some writers have noted the difficulties with assuming that people should be or want to be 'empowered' (Stalker, 1998: 6; Stone and Priestley, 1996: 711; Hammersley and Atkinson, 1995: 286-7) and others advocate that the goal of researchers 'should be neither moral judgement nor immediate reform, but understanding' (Lofland and Lofland, 1984: 29). Participants with learning difficulties in this research were not 'politicised' (Stone and Priestley, 1996), and I was certainly ambivalent about my ability or right to politicise people who had not invited me into their lives.

Secondly, questioning the 'oppression' inherent in the structure of care delivery may compromise the researcher's ethical commitment to staff. There is a double-bind here, in that while ethnography offers the opportunity to examine how such 'disablement' might look at source (through the *contextualised processes of interaction* that constitute front-line care), engaging in such contextual research necessarily produces a commitment to *all* participants in the context (Poland and Pederson, 1998: 298-9), in this case a commitment to staff as well as disabled residents. At times I have felt my analysis does reflect negatively on staff, yet I have actively sought to understand their perspectives and throughout the research to informally discuss my interpretation with participants.

Thirdly, another response to the power differential asserts that researchers should share the standpoint of the participants (i.e. also be disabled, female, etc). However, contextualised research necessarily involves *both* disabled and non-disabled people, so my own disability status could never provide a 'standpoint' for both sides. Ethnographic

research may take as its participants people with *many* different standpoints, a disabled researcher for example, would thus not be able to take the standpoint of the non-disabled staff. However, it is useful to consider that 'disability' is not a heterogeneous experience and disabled researchers do not automatically have 'an affinity with [all] disabled people' (Barnes, 1992: 121). Barnes suggests that by regular, prolonged interaction, continuous feedback and awareness that access is an ongoing negotiation, power asymmetries can be addressed (ibid: 122-3). My conclusions have been, then, to act with respect to *all* participants, to resist and question potentially exploitative and oppressive practices I witness and participate in, to *continuously* negotiate permission to observe and to adopt a reflexive stance. In Heyl's (2001: 377-8) terms, this reflexivity is admittedly 'weak' (an ongoing consideration and awareness of my role) rather than 'strong' (active empowerment of participants), yet she asserts that 'weak' reflexivity may also play a valuable role in considered and ethically sound research.

'SILENT PARTICIPANTS- SPEAKING VOLUMES?': REPRESENTING PEOPLE WHO LACK WORDS

Issues of power permeate the research. In my observations, I have also felt concerned to represent the meanings and perspectives of those participants with learning difficulties who 'lack words' (Booth and Booth, 1996). Emerson et al underscore the power of language in ethnographic work:

'Authors who insert voices from the field construct a tone of authenticity in their texts. In effect the writer says to the reader, 'I was there and *this is what I heard someone say*'. By presenting vivid characters who speak in their own idioms, the ethnographer creates an engaging text which invites the reader not only to think about the argument, but also vicariously to

experience the moment. Such rhetorical strategies persuade'.
(2001: 365. Italics mine).

Hammersley and Atkinson (who notably only discuss words and documents as potential ethnographic sources) similarly comment:

'all human behaviour has an expressive dimension... However, the expressive power of language provides the most important resource for accounts' (1995: 107).

When not all participants communicate primarily in words, the words of those participants who are verbally articulate are perhaps more powerful, more 'authentic'. As I have discussed, ethnography, as opposed to interviewing, provides an opportunity to consider expressions that do not necessarily take verbal forms. In considering my approach to data generation (and data representation) I have also sought to address the potential power imbalance in the following ways:

1) Ethnographers are generally advised to distinguish clearly in fieldnotes between what is observed (events and actions) and what is heard (dialogue and speech) (Emerson et al, 2001: 359) and between verbatim quotations and paraphrasing (Hammersley and Atkinson, 1995: 184). It is tempting to feel that verbatim quotations constitute 'better' evidence and to think of language as a 'truer' or more 'faithful' representation than descriptions of observations.

However, this is perhaps a false dichotomy. Even linguistic transcripts do not represent all the nuances of a piece of dialogue and 'at every step an ethnographer *recreates voices...*' (Emerson et al, 2001: 364. Italics mine). Moreover, in seeking to represent non-verbal voices and contextualised interactions which do not rely entirely on words, I have found that the observed and the spoken intermingle. Words are given meanings by actions, and vice versa. Privileging words and 'quotations' means that people who do not communicate in words are likely to be

excluded and denied a 'voice' at all. Consequently, in generating data and representing observations I have purposefully not distinguished between verbatim quotations or spoken words and my own descriptions of scenes and interactions (cf. e.g. Barnes, 1990).

2) Communication can take many forms. Poland and Pederson point to the possibilities for 'transcribing' what is expressed through music, through pauses between words, emotions and dance (1998: 302-3, see also Ellis, 1995). Eloquent expressions can sometimes take tactile (e.g. Twigg, 2000: 47) and gustatory forms (e.g. Stoller, 1989: ch.1). Coffey also points to the importance of the physical in fieldwork; 'our bodies and bodies of others are central to the practical accomplishment of fieldwork' (1999: 59). As such, I have consciously sought to include detailed accounts of interactions that are based on such non-verbal, visual, gustatory, tactile and emotional understandings, hoping that this will allow a place for word-less voices (see also Corbett, 1998; Puddicombe, 1995).

For example, in negotiating consent for access I attempted to listen to residents' views on my presence:

On one occasion, on arriving, I went to say hello to Bob (who has a vocabulary of less than five words). He was in his room, in a chair listening to some stirring classical music. I commented on how nice the music was. He laughed, and began to 'conduct' the music, ostentatiously waving his hands in the air. I felt delighted that he had responded to me, - last time I'd tried to talk to him, he'd not even looked at me. I laughed and 'conducted' too... Later, in the living room I was sitting with Bob and Chris watching TV and talking. When the advertisements came on, one had a classical soundtrack. Bob again began to 'conduct', he caught my eye as he did so, and laughed. We spent some time that evening watching TV and intermittently 'conducting' at appropriate moments. I felt that we had communicated

much more than on previous visits and that Bob had expressed that it was OK for me to watch TV with him. There was a relaxed, friendly feeling that we could sit together, sometimes acknowledging the music, and each other, and that to some extent Bob had communicated his acceptance of my being in his house.

SUMMARY

Grappling with methodological considerations highlights how ontology and epistemology are interwoven with ethical and political considerations. Gaining access, informed consent, generating and representing data are all impacted by the power dynamics of disability research. Although I have consciously endeavoured to include the voices of people with learning difficulties in this study, I am aware that I have not fully resolved the questions of power and exploitation. My research is therefore presented as an *engagement* with these issues, rather than a *solution* to them. I turn now to the presentation of some of the data I generated with these concerns in mind.

CHAPTER 4

'WELCOME HOME': RESIDENTS AND STAFF AT NUMBER 42, OAK LANE

'Supported living, that's the 'thing' at the moment'

CATHY

Manager of 42, Oak Lane.

OUTLINE

This chapter provides a short sketch of the house where the research was conducted and an introduction to the residents and staff that lived and worked there. I will draw attention particularly to some of the ambiguities and issues in the definition of the house as a 'home', and in staff's understanding of it as a 'supported living' house. These considerations set the scene for the negotiations which I explore in more depth in Chapters 5 and 6.

NUMBER 42 OAK LANE

The house is situated in a working-class suburb of a small Yorkshire city. It is a quiet neighbourhood, where a small collection of shops, a couple of pubs and a fish and chip shop sit on the hill from which Oak Lane descends. Number 42 is a modern chalet bungalow, set back off Oak Lane which is lined with a medley of terraces, semi-detached and detached houses of diverse historical provenance.

Having first spoken to managers both at the local council and at the Fairlee Foundation, my first visit to the house was to meet with Cathy, the manager. This first visit highlighted some of the ambiguity I was to see throughout my research at the house.

Entering the house, which was pleasantly decorated, sunny and light, the first thing I saw was a decorative blackboard hanging on the hall wall facing the door: the kind of blackboard where shopping lists and notes might be jotted. In a careful firm hand, someone had written in chalk 'Welcome Home'.

Cathy ushered me into the kitchen and asked me if I wanted a cup of tea, explaining that the residents were all out at day centres or other community activities. She showed me into the living room, where we sat with our tea and she began to talk to me about the house, the Fairlee Foundation and the people who lived at Number 42 and their needs... 'As for the residents, we don't have any 'Challenging Behaviour' here, but some of them *do have* challenging behaviour!' she laughed.

Cathy acknowledged the world of care where (by a kind of metonymy) people with 'challenging behaviour' themselves become known as 'Challenging Behaviours' and where only *some* people are officially classified as having such behaviour, while others are not, despite the 'challenges' staff feel they present.

Number 42 is one of many houses owned and managed by the not-for-profit Fairlee Foundation, who provide support services to adults and children with learning difficulties. Cathy told me about the Foundation's various houses which over the last few years have become smaller, more intimate and less institutional;

'There's only one of the large 'registered' homes left now. The others have all become 'supported living'. Everything's supported living now, that's the *'thing'* at the moment' she confided.

Cathy's presentation of 'supported living' as a 'thing at the moment' was in some part mediated by her understanding that current buzzwords and terminology may not always reflect the reality of care-work. However, 'supported living' is certainly a nebulous concept. Means and

Smith note that 'supported housing' is often used as a generic term to describe a diverse range of living situations where formal care or support is combined with housing: including residential care homes, sheltered housing and staffed shared housing (1998: 175). Housing such as that at Number 42 is also variously described as 'small scale ordinary housing' (Valuing People, 2001) or 'private/voluntary homes' (Fitton et al, 1995: 2) or a 'staffed group home' (Cambridge et al: 24), the latter characterised by 'continuous staff coverage, including [coverage] over night and 2-5 places'.

RESIDENTS AND STAFF

Number 42 was home to five residents and seven staff (as well as Cathy) provided support. Five female and two male support staff ensured 24 hour coverage at the house. During the day there were usually two or three staff present, and overnight one staff person provided a 'waking night' cover in the home while another slept at another Foundation house next door to be 'on call' for emergencies. John, Jackie, Sasha, Clare and Katie were all in their thirties and lived with partners and in most cases, young children. Linda and Mark were older, both in their early fifties with grown-up children. Without exception, staff lived in the local area and had done for at least the last five years, but most had lived in the city for the whole of their lives. Their families, histories, knowledge and accents were intimately connected to the area.

All five residents also had strong local ties, and all had a family member living in the city. All had lived locally with their families for a substantial part of their lives. For Ben, in his twenties, this was his first home away from his parents. Ben had moved in three years ago. Chris, Bob and Diane (all in their thirties) had all lived together at Number 42 for five years, and prior to that with families and in large staffed 'registered care homes'. Ben, Diane and Bob had somewhat limited speech, each

had a vocabulary of between five and ten words. Chris was more 'verbally articulate', yet was quietly spoken and it took me some time to understand his speech well. Soon after I began visiting the house, Roy moved into the remaining empty room (vacated by a resident who had moved into an independent living flat). Roy was in his early forties. He had lived with his mother for some time, in some staffed homes and most recently in an 'independent living' flat on his own, with less intense staff support. Roy had found this very difficult, and after some time in hospital had moved into Number 42.

'A HOME OF ONE'S OWN' ?

Residents rented the house directly from the Foundation, and had leases in their own names. Cathy mentioned that although the house had formerly offered 'respite care', it had been decided several years ago that strangers coming to stay temporarily in 'someone's home' was inappropriate and the house should be exclusively for permanent residents. The Foundation's stance is that Number 42 is the *residents'* home, and staff are there to support residents to live in their 'own home'. However, as I will examine, the subtle and metaphysical implications of 'one's own home' are not necessarily encompassed or explained by tenure alone. The presence of staff in the home in particular, presents a challenge to the notion of one's own home.

For example, it was evident that staff played a significant role in shaping the environment as 'home'. The kitchen was pleasantly decorated, painted yellow with a large oval pine table in the centre, and floral curtains, but the *only* picture on the wall was of a gaggle of ducks approaching a farmhouse which was entitled 'Coming Home' in large italic script. As for the 'Welcome Home' message on the blackboard, after six months of visits the message remained the same and was still the only one on the board. Given that only one resident was able to read

(and that he moved in during the course of my visits), it seems clear that these particular linguistic reassertions of the house as home were made both by and for the staff. Staff, it seemed, were making a 'home' in an ambiguous space, a 'home' which was perhaps in some ways *not* home. The negotiation of the house as 'home' (and staff control over those negotiations) is a theme which I turn to next as I examine how staff and residents understood Number 42 in the context of associations between 'home' and 'family'.

'KEEPING IT IN THE FAMILY?'

THE FAMILY AS A MODEL AND TOUCHSTONE FOR HOME LIFE

***'The house is normalised by the family and the family is normalised
by the house'***

JENNIFER CRAIK

'The Making of Mother', 1989: 57

OUTLINE

In this chapter I will examine how participants interpret the association of 'home' and 'family' in a non-family home. I will look at how 'family' provides a model for decision-making, interactions, and the conceptual framing of this house as a home. The role of participants' family homes will also be evaluated, and the interaction between the 'family model' of home and the practical exigencies of a workplace will also be discussed.

HOMES, FAMILY AND CARE

'Home' and 'family' are mutually defined and validated, and often perceived as synonymous (e.g. Allan, 1989: 142. Allan and Crow, 1989). For some non-kin households, the house may not be even experienced as a 'real home' without a family group (Higgins, 1989: 171, Allan, 1989: 144, 142). As I will show, however, non-kin groups may consciously and unconsciously model their household on a family unit, thus restoring some 'normality' to a potential 'abnormal' home, as Craik writes; 'the house is normalised by the family' (1989: 57).

Significantly, residential support for older and disabled people is *also* inexorably associated with family. Such care (i.e. its perpetual nature, the

spontaneous response to emotional and intimate physical needs), often evokes in paid care workers (and observers) a comparison with 'pervasive ideals or models of care... which occur within traditional kinship boundaries, especially the "informal" care of children by parents' (Willcocks et al, 1987: 54; see also Twigg, 2000: ch 8). Particularly in the absence of any formal training; 'most care staff approach the task of residential care from a background of common sense caring and experience practised in the domestic setting' (Willcocks et al, 1987: 63). This familial model of care is a gendered one, (Finch, 1984) as it draws particularly on the care of children by *mothers* (ibid: 54) and reinforces the 'naturalness' of women as both paid and unpaid care-givers (Finch, 1984: 10-11, see also Twigg, 2000). Furthermore, the model of familial care has special resonance in support services for people with learning difficulties since they are readily perceived as 'perpetual children' (Stalker, 1998; Jenkins, 1996). Typically, people with learning difficulties also live with their parents until parents themselves need support (Valuing People: sec 7:1), consequently formal care is often a *direct substitute* for care by the family.

For these reasons above, 'the family' provides a particularly salient metaphor for residents and staff in understanding the home, both explicitly and implicitly, although as I will discuss, use of the model is sometimes contested and ambivalent.

MAKESHIFT FAMILIES:

i) PARENTS AND CHILDREN

Staff and residents drew particularly on the model of 'parents and children' in understanding their place in this home. For instance, the household's newest resident, Roy, discussed his feelings about this new home in terms of his family history. Roy and I were chatting at the table:

We'd returned from a birthday outing for Bob. We discussed birthdays in general, our own and others', I asked Roy how old he was, he told me he would be 44 next birthday. Roy was interested to know what day of the week it will be, so we looked it up in my diary.

'It's funny, I'm not the youngest anymore' said Roy.

'In this house?' I asked.

Roy thought for a moment 'Ben's the youngest then Diane and Chris and Bob. They're all younger than me. I'm the oldest now' he replied. Roy had obviously taken some trouble to find out his place in the order of things, even though he seemed quite shy and staff often said he had not interacted much with other residents.

'I'm not the youngest anymore. It's funny 'cause I've always been the youngest'. We talked about his five brothers and sisters, 'when I lived with my mam, I was the youngest. Now I'm the oldest' he said again.

'Do you like being the oldest now?' I asked

'It's funny, I'm not used to it' replied Roy.

Allan notes that 'the home is the normal, expected place of kinship interaction... [and that] privileged access to the home symbolises the solidarity of kinship' (1989:146). For Roy, despite having lived in his own flat, home was naturally the place of kinship and sibling relationships. He made sense of this home by comparing himself and the other residents implicitly to children in a family.

On another occasion, staff members John and Katie were discussing some of Chris's behaviours, which were discouraged and perceived as unusual. Chris would often talk to inanimate objects in the house, spending sometimes 10 minutes 'chatting' to a household appliance such as the washing machine.

Katie commented 'my little one, he does just the same thing, find him talking to things like they could talk back! He's four years old, I think Chris is at that same stage'

John agreed, 'yeh, I know what you mean. I'd say he was at a four old level with the way he talks and his vocabulary and that, thinking what my two were like when they were that age'

People with learning difficulties are often compared to children and assigned a 'mental age' or their development considered to be arrested, or 'retarded' (Jenkins, 1996). John and Katie's comments were not unusual then, but their reference to their *own* children powerfully reinforced the metaphor of staff as parents and residents as children in a pseudo-family home.

Decisions on how to spend the household's budget also borrowed from this idiom of 'parental' control and guidance. Cathy informed me that the Foundation organised a fund-raising every year. Houses each held a cake sale and anything they raised over £100 was available to be used by that household at its own discretion. Having raised £300, Cathy said:

'We've got £200, so the staff have decided to spend it on a chest freezer. I mean, it just makes it easier to take advantage of special offers, and it's often cheaper to buy in bulk, and then we can keep cakes for the next sale...'

I wondered if I looked disapproving, because Cathy continued to justify the decision. I said 'yeah, it makes sense. You can save a lot of money when you can buy more and freeze it...' and Cathy seemed pleased, relieved that I understood.

Clearly Cathy was aware of the awkwardness of household decisions being made by (and somewhat for) *staff*, yet she also expressed how reality of social care meant that their decision was driven in large part by economic imperatives.

Other research has found a similar pattern where residents with learning difficulties may have responsibility for chores in their *personal space* (i.e. bedrooms), yet staff retain control and responsibility for

'communal and household-level tasks (such as household finance)' (Cambridge et al, 1994: 31). However, far from offering people with learning difficulties a degree of independence, as Cambridge et al claim, this division of responsibility also reinforces a parental idiom, where adults with learning difficulties play the role of children while staff make the decisions generally reserved for parents. This lack of an 'adult' role is reminiscent of Goffman's description of total institutions which deny residents 'adult executive competency' and concomitant adult freedoms (1961: 47).

ii) GOING SHOPPING

Use of the parental model was apparent in other household spheres, such as shopping. On one occasion, I accompanied staff and a resident to the supermarket:

Ben seemed happy to walk alongside the trolley while Jackie and John dropped items into it busily; occasionally conferring amongst themselves about what was needed or useful. Occasionally I helped out by fetching things.

Jackie called Ben over to a rail of T-shirts. She selected one and held it up against his chest. 'That'd fit you wouldn't it?' she said. Ben did not pay much attention and moaned 'hmmmmm'. 'OK, we'll put a couple of those in. You could do with some new T-shirts'

John inspected the shirt. 'Oh, they're nice, I'll get some for Chris too' he said, (the resident for whom *he* had informal 'key-worker' responsibility) and added two similar shirts to the trolley...

Jackie later saw some packs of socks on offer as we passed by the children's clothing section.

'Liam [Jackie's son] could do with some more socks, I'll have a couple of those' she said, and placed them separately in the top compartment of the trolley.

Although residents also shopped individually with parents or staff specifically for clothes, (where presumably they were more involved) the parallels of parental decision-making in this instance are evident. Simultaneously finding items for their own families too, underscored the role that staff were playing of 'parent' in their professional lives.

Once at home, shopping was hurriedly unpacked by the staff, without comment, while residents sat in the kitchen or watched TV in the lounge. Decisions over where supplies are stored are again a manifestation of control over one's home (e.g. Twigg, 2000: 84). Jackie did draw Diane's attention to some ingredients she had bought so that they could make chocolate cornflake cakes together, although this is notably a leisure activity rather than cooking a meal, and again recalls the parental idiom of baking with children.

iii) EATING AND COOKING TOGETHER

The preparation and consumption of food also underlined the parental model, and the familial model more generally.

On my first visit to the house I declined an offer to eat dinner, which was served while I was there. Mark had been sitting with Ben in the lounge. 'I'm just keeping him out of Clare's hair while she gets the dinner' he said.

Cathy had suggested previously that I stay to take part in 'aromatherapy evening' that night, and I assumed that I could simply wait while the residents ate. From past experiences in similar settings I had expected that staff would not eat with the residents. However, when staff and residents sat down to eat *together* at the table, I felt excruciatingly uncomfortable as I waited, also in the kitchen with them, feeling that I was intruding unacceptably.

My discomfort, while an example of the awkwardness of fieldwork (e.g. Lofland and Lofland, 1984: 32) also violated my own expectations of

family-like activities in the house, indicating a more familial approach than I had expected.

Both cooking and eating, however, exemplified staff's tendency of 'doing to and for' residents, rather than allowing residents to do things themselves (Higgins, 1989: 171). The kitchen is of central importance 'the place where family life often centres' (Bordo et al, 1998: 77). Furthermore, cooking is also 'still denoted as the primary element of house-making' (Craik, 1989: 53). Staff, as cooks were in this sense the 'primary house-makers' while residents relatively passive recipients of their services.

Cooking is, of course, a gendered activity located in the gendered space of the kitchen (Craik, 1989; Twigg, 2000: 95, Bordo et al, 1998). Mark notably kept Ben 'out of Clare's hair' to allow *her* to cook. While male staff also cooked, female staff's role at meals certainly underlined the performance of gendered familial roles. During my visit, female staff remained alert to residents' potential needs, jumping up to offer second helpings and drinks while male staff got up only to get second helpings for themselves. Hunt observes that while middle-class housewives are 'managers' of meal times, a working class housewife resembles more closely a 'servant' who 'consumes her food in between the interruptions required in order to meet her family's requirements' (Hunt, 1989: 71). Not only is family life a model for the household, but the values and roles are perhaps those of a *working class* family life.

The act of sharing food symbolises intimacy, closeness, familiarity, trust and acceptance. Twigg writes that eating with others presents a symbolic risk of 'pollution' from those others, while overcoming this fear and 'sharing the bodily functions implies a form of equality' (2000: 152). Eating together was perhaps more reminiscent of a family home than the structure that may be expected of staff as supporters in the *residents'*

home. Later in the meal, an explicit reference to the familial model was made:

As they ate, Mark began to joke with Ben, whose hands were dirty from handling a newspaper. Ben laughed at being teased. Ben continued laughing and Chris also started to giggle, Mark commented, with some irony 'we're all one big happy family here'. Ben seemed to find this comment very amusing, and burst into laughter again. Mark said 'is that funny? You like that?' and repeated his comment, (somewhat sarcastically, I thought) 'oh yes, one big happy family'.

Clearly, the use of the metaphor is shot through with the irony, awkwardness and amusement evinced when it was made explicit. Although I have shown that the household referenced 'families' in making sense of the living situation, residents and staff were well aware that it was far from being a 'real' family home, an issue to which we now turn.

'HOME IS WHERE THE HEART IS' : EMOTIONAL ATTACHMENTS TO OTHER HOMES

Most residents in Number 42 had lived with their parents for a large part of their lives. Frequent visits 'home' and staff's contact with parents reinforced the idea that residents were effectively living in a substitute family home, a 'fill-in' between trips to see parents and a continuation of parental care which had broken down but should be perpetuated (cf. Willcocks et al, 1987: 67). Some residents also considered their family homes to be 'home'.

For example, Ben visited his mother every other weekend, and appeared to look forward to the visits. Ben's verbal conversations usually consist of only the phrases 'Mum coming?' 'Go home', 'Mum, home' and occasionally, 'alright'. Ben will often repeat these phrases many times, and tap peoples' arms to get attention in order to ask his questions. Mostly, staff respond 'yes you'll go (or you went) home at the weekend'-

reaffirming that 'seeing Mum' is synonymous with going 'home'. Sometimes staff (and residents) respond differently, however.

Ben was sitting at the kitchen table, speaking to staff and myself. 'Go home?' he said.

'Do you want to go home?' I asked.

'Oh yes, he loves going home to see his mum' said Sasha, 'you went last weekend didn't you?'

'Mum... go home!' cried Ben.

'I know, but you can't go home every weekend, your Mum'll think we don't want you here!' laughed Sasha.

Some residents used few words, yet considered in the context of interactions, these words spoke volumes. Ben's emphasis on going 'home' to see his Mum means the identity of the house as a 'home' is often threatened. Sasha reasserted above that it was inappropriate to go 'home' too often, since Ben actually lived at Number 42. Sometimes staff would correct themselves more explicitly:

I went with staff to drop Chris at his parents' house. Ben was also in the van. As we pulled up to Chris's parents', Ben said 'go home?'

'You're not home, but yes this is *Chris's* home' responded Katie. After a pause, she corrected herself, 'this is where Chris's *mum and dad* live'.

Katie attempted to reassert the 'home' status of Number 42, in the face of other (emotionally charged) homes potentially vying for the status of 'home'. Adult children may consider 'home' to be where they grew up and their parents still live, (Marcus, 1997: 2), sometimes contentiously (Mason, 1989), yet residents' and staff's automatic assumptions that 'home' is elsewhere also undermine the house's claim to status of 'home'. Sometimes other residents found this a troubling issue, Chris was usually very quiet but on one occasion expressed his discontent.

We were sitting in the living room, residents were watching TV and leafing through magazines. Ben had been saying 'go home', 'Mum home?' 'Mum coming?' 'going home?' repeatedly for ten minutes or so. Mark had been offering Ben reassurances that 'yes you'll go home at the weekend'.

At one point, however, Linda responded quite firmly 'you *are* home. This *is* home'. Chris repeated, to Ben in a strained voice, 'yes, this *is* home. Shut up, you *are* home'.

I had never heard residents react to Ben's questions at all before, but it seemed that tonight, Linda's words struck a chord with Chris and gave him a cue to express his feelings about the home.

This home is understood, then with reference to *other* homes (and families) outside of its physical and literal boundaries. Daly and Dienhart note that the domestic arena has 'diffuse definitions and elusive boundaries' (1998: 99)⁷ and is understood through temporally and spatially dispersed meanings and understandings (see also Gubrium and Holstein, 1997: 78-9). This forces participants to enter into negotiation about its status as a home. Staff's other homes also impact on this understanding.

A HOME FROM HOME? : STAFF'S COMMITMENT TO THIS AND OTHER HOMES

For some staff, Number 42 carried some of the emotional resonance associated with home. Staff and residents often shared long histories, spanning significant parts of both their lives.

'I've worked with Diane for 10 years now' said Linda to me, then addressing Diane; 'we knew each other back in The Elms, [a large

⁷ Although Daly and Dienhart's ostensible focus is on studying 'the family', this overlaps significantly with their concept of 'home' (1998: 102-3).

'registered' home which has now closed] and when you moved here I started just after didn't I?'

Diane nodded. 'We know each other well by now, don't we?' she said. Diane came over to where Linda was standing and gave her a hug. Diane was usually very quiet and reserved and this was the only time I saw her hug anyone at the house. 'Oh yes, we've been through a lot actually' said Linda.

Finch argues that although family-based care offers intimacy, residential care 'almost certainly involve severing affectional relationships and dividing 'caring for' from 'caring about'' (1984: 16). In contrast, however, I would assert that the choice is not so stark. Residential support staff in using a familial model of care, may also 'care about' as well as 'care for', and over time, may forge and maintain deep and significant 'affectional relationships'.

Nevertheless, staff's family homes also played significantly into their understanding and use of Number 42. Working evenings and night shifts in the home impacted directly on their family lives:

Mark had worked all day today and was due to sleep in tonight, to cover for another staff person who had called in sick. 'My wife won't have seen me for 24 hours when I get home' he said. 'That's too bad' I commiserated. 'Oh no, she said she was glad to have me out of her hair' he laughed. He said they'd been married for 27 years. 'That's what its like when you've been married that long. I said to her, last anniversary - I'd have got off with a lighter sentence if I'd done the Great Train Robbery!'

Staff were always professional and engaged, yet seemed sometimes to attempt to 'reclaim' some of their own (lost) family time while at work. For instance, after watching Coronation Street one evening, John spoke to his wife on his mobile phone during his break and they discussed it. Unable to watch it *with* her, he caught up on 'family time' as best he

could. That Number 42 was not his home was highlighted by this, especially when he laughingly commented that he had explained to her that he could not follow some of the plot because Ben had been fervently asking about 'going home'. Staff did not indicate resentment about their work, Mark and John used humour in these incidents, and Katie's grabbing an item to buy while at the supermarket merely took advantage of an opportunity, yet their family homes were certainly not Number 42.

As Willcocks et al remark, 'residential care work [is] a job to be fitted between family commitments, and perhaps an extension of these' (1987: 72). Care is not only *modelled* on family but occurs very much in the context of and *in relation to* other families. Staff's use of the home is as related to their families as is residents' understanding. Indeed, as I noted in Chapter 3, my own biography and family history also played into *my* understanding of the home, and ironically, alerted me to the 'family-like' nature of the home despite (or perhaps because of) the congregation of unrelated separate users and inhabitants. However, while understanding the home in contrast to *other* family homes sometimes illustrated its family-like quality, it was impossible to forget that the home was not a family, a fact which was starkly evident at times.

'DYSFUNCTIONAL FAMILIES?': AMBIGUITIES AND CONTRADICTIONS IN THE FAMILIAL MODEL

The familial idiom operates in a wider society where modelling formal care for adults on the family's care of children may be considered demeaning and inappropriate. The family metaphor of care is used overtly in some support services, for example; adults with learning difficulties may live with 'house-parents' in Camphill Village Trust communities, or be 'fostered' into existing families (Williams, 1995: 85; Finch, 1984: 10). However, such overt manifestations of the family

metaphor of care are often contentious: the director of a controversial documentary about a home where adult residents with learning difficulties received weekly 'pocket money' and called the managers 'Mum and Dad' observed that the home worked well *because* of 'the idea of its being family... [but] social services don't approve of that' (Matthews, 2003; see also Brindle, 2003). Although Valuing People (2001) advocates support for people with learning difficulties in 'ordinary small scale housing' it avoids suggesting that what makes houses 'ordinary' and more 'appropriate' than institutions is that they are closer to *family-scale* residences, nor that they should attempt to emulate families.

The familial model of care has also been criticised as a euphemism for care by females which perpetuates and depends on patriarchal oppression (Finch, 1984: 10). Others believe that it disempowers individuals, by failing to focus on individual, perhaps idiosyncratic support needs (Willcocks et al, 1987: 142). In summary, although the 'family model' may offer a way for informally managing a home and the care within it, it brings much criticism and is rarely an 'officially' sanctioned understanding.

Although it may draw from a family idiom, 'when care work is performed under the conditions of waged labour, this [family and kin based] anti-structural, totalising ethic of love meets and clashes with the principles of economic rationality and the highly structured, measured conditions of formal employment' (Twigg, 2000: 170 see also Willcocks et al, 1987: 54). The familial model is a *metaphor* for making sense of and managing the home but the house is, of course, *not* a family home. At times life in the house contrasted starkly with 'family life'.

Chris and Bob and I were watching TV. Chris came and sat next to me and leaned against me. 'I love you Becky' he said. I smiled, but as Chris remained leaning against me, I was aware that such (prolonged

and familial) intimacy felt acutely uncomfortable for me, and felt inappropriate for my role there, especially with 'vulnerable' people. I had seen staff occasionally hug Chris, as he often asked for physical contact, yet I realised suddenly that Chris never had the opportunity to curl up on the couch with others, to experience the sustained physical contact that for most people is part of being 'at home' and is certainly part of family life.

I disentangled myself from Chris and suggested we play cards, which he agreed to happily.

Other staff also mentioned a sense of ambivalence about the closeness of their relationships. Jackie explained how on a household vacation

'I was Ben's one-to-one supporter, so I had to stick with him most of the time, you know- keeping an eye on him. But Mark kept singing 'Me and My Shadow' every time he saw us together, the whole week. It was just my job, 'cause we get on well, me and Ben. It's not like there was anything funny about it'

Mark's reaction may have been idiosyncratic, yet Jackie's own sense of awkwardness at the sustained intimacy that week with Ben is also evident. Staff were aware of the difficulties between maintaining intimacy and the ever-present risk of being accused of abuse. Nevertheless, the ambivalence about such intimacy does shake the family idiom which is so successfully employed elsewhere, contradicting the rhetoric (spoken and unspoken), that the home was in some way a 'family'.

Higgins remarks that 'even allowing for the less than idyllic relationships which some people have with family and friends in their own homes, the opportunities for satisfying social relationships which exist in residential homes seem markedly fewer' (1989: 166). Relations in Number 42 were not 'unsatisfying', yet relationships were often lacking

when compared to the intimate, unbounded and empowering *ideal* of familial love.

CONCLUSIONS

I have shown how 'the family' offers an important point of reference in understanding the home. In particular, perceptions of 'care-work' and of the 'child-like' nature of people with learning difficulties make it conceptually easy for staff to adopt a 'parental' model of care in their work. Staff's influence over daily activities and decisions in the home is ordered and legitimised by this model.

For residents, family homes also provide a powerful model for negotiating this house. Their emotional attachment to family homes also provides a contrast and comparison to Number 42. Consequently, staff and residents sometimes struggle to clearly define Number 42 as 'home'. Staff's family homes also play a role in defining the home, and their work impacts on their family lives. This home is then, constructed dynamically in relation to other (family) homes and with reference to perceived norms and ideas concerning the family and the home.

The family model is, however, full of ambiguities. Although it offers a way of 'normalising' an unconventional home, it also raises a number of problems. Residents are often placed in the position of children (disempowered and infantilised), oppressive gender roles are perpetuated and the disparity between and the norms and exigencies of a workplace sometimes exposes the incomplete and compromised reality that approximates to 'family life'. The difficulties in the use of the family idiom highlight the latent power structure in the home and the sometimes surprising discrepancy between this home and 'home' as conventionally understood, an issue which I will now explore further.

CHAPTER 6

‘LUXURY AND PRIVACY AND SPACE’:

NEGOTIATING AND DEFINING BOUNDARIES, PRIVACY AND SPACE IN THE HOME

***‘I thought too... of the urbanity, the geniality, the dignity
which are the offspring of luxury and privacy and space.’***

VIRGINIA WOOLF

‘A Room of One’s Own’, 1929: 23

OUTLINE

Issues of ‘privacy’ are central in understanding home. In this chapter I will examine how negotiations around the definitions of the public, communal and private aspects of the house shed light on the meaning and management of the home for participants. I will explore how these negotiations intersect with the use of the ‘family’ idiom outlined in Chapter 5 and how the meaning of home in the house also needs to be understood in the wider context of power dynamics between staff and residents.

LOOKING AT PRIVACY

Consideration of ‘family’ and ‘home’ leads naturally into an analysis of the interconnected notions of privacy and space, which also are important in the meaning of home. Rybczynski (1986/2001) notes how the modern understanding of the family emerged/evolved in tandem with the association between home and privacy (1986: 60). From the late middle ages, ‘the house was becoming a more *private* place. Together with this privatization of the home arose a growing sense of intimacy, of identifying the house exclusively with family life’ (ibid: 39), shaping our perceptions of home until the present day.

As I have discussed, the 'private/public' and 'insider/outsider' division often marks family from non-family, and bounds the house, providing privacy for its residents (e.g. Allan, 1989). Mason notes that what is 'sociologically compelling about these apparent dualities [of private/public] is the way they intersect and *operate in social and power relations*' (ibid. Italics mine). In Number 42, these power relations played a substantial role in shaping and understanding the home space.

'OPEN HOUSE' : STAFF'S CONTROL OVER SPACE AND BOUNDARIES IN THE HOME

The boundaries of 'in/out' public and private in Number 42 were sometimes unlike the boundaries of a 'conventional' home. Arranging my initial access, (and all subsequent visits) through the house's manager highlighted the decision-making power senior staff held over the admittance of outsiders to the house. Cathy specified that each visit had to be pre-arranged with her, by telephone, and the date recorded in the staff schedule. Cathy's organisational imperative also meant that support staff and residents were not consulted about my visits. There is a striking contrast to the power most people have over their own homes where they can decide '...whom they choose to admit through their front door' (Higgins, 1989: 172; see also Twigg, 2000: 82).

Although I gained access readily, I was not necessarily granted 'insider' status. In my earlier visits, Cathy frequently referenced the progress of my criminal record check, noting that when it was eventually completed I could 'take people out' which seemed to be the volunteer/befriender's primary role. The imperative to 'go out' seemed to 'normalise' my presence (and the home itself, see Craik, 1989); since volunteers are framed then as friends who socialise with residents rather than forming part of a formal structure of care in an unconventional 'home'.

Other staff also emphasised 'going out' as opposed to spending time in the house, although here the undercurrent was also that I should want to witness residents' behaviour and activities across a variety of environments. In this way, residents' 'private' lives were made available for 'public' view. For instance, Mark insisted that I accompany Sasha, John, (staff) Ben and Chris (residents) to the supermarket, saying that it was important I should be able 'to see them [the residents] when they're out, get a picture of what they're like out of the house'.

When I got into the van, John asked me: 'How did he sell it to you, then, sending you out?'

I told him what Mark had said.

'Hmmm', said John, 'well you'll only get to see Ben out, cause we're dropping Chris off at his Mum's for the evening. You'd see more coming out to the pub one night, that way *everyone's* there' said John.

'Perhaps he just wanted to get rid of me' I laughed, not wishing to slander Mark, but failing.

'Oh no, it's not you- he just wanted to be free to watch the telly all night' John said.

'He never goes out, he'll just be watching TV. The football's on tonight, you see' Sasha added.

'You know, he wouldn't come out last week either when we did the shopping then. There's nothing to do there tonight, once Bob's had his bath, he'll just be sitting around till we get back' John said.

This incident illustrated Mark's assumption that I wanted only to observe *residents* and indeed that such observation was entirely legitimate. The lives of disabled people, like those of children, are often assumed to be 'open' to view (Hammersley and Atkinson, 1995: 75). Simultaneously, however, this incident also pointed to how the staff attempted to balance their understandings of work (a formal, public

sphere activity) with the fact that they were in, and were maintaining a home.

'WORKING FROM HOME' : STAFF CLAIMS TO *WORK SPACE* IN THE RESIDENTS' HOME

John and Sasha's comments about Mark highlight the negotiations which frequently took place around staff not treating the house too much 'like their own home' e.g. by relaxing and watching TV rather than performing chores. Maintaining a 'home' yet being at 'work' was a difficult negotiation for staff (e.g. Marcus, 1997: ch 7).

Attempts by staff to avoid appearing too much 'at home' in the home may have influenced the amount of 'paperwork' which was performed visibly in the house. Personal and domestic support is often intangible and difficult to quantify. Workers, keen to produce concrete results, may 'translate their concern into material expressions' (Willcocks et al, 1987: 59), in this case, paperwork. Staff's work (consulting the schedule, discussing rotas and work issues, consulting residents' log books) was typically a significant presence in the kitchen. The (locked) staff office upstairs was used mainly for storage and staff usually worked at the kitchen table, which was also the central gathering place for residents and guests to sit and drink tea, look at magazines or chat.

The kitchen is central to understanding domestic life, it has been considered 'the control centre of domestic space' (Craik, 1989: 48; Bordo et al, 1998). Significantly this core area of the *home* became also the focal point of *work*: bureaucracy, scheduling, discussing work matters and the paperwork of carework.

Female staff frequently also offered to make drinks for both visitors and residents returning home or gathered in the kitchen. Freedom to offer refreshments to others is 'in accordance with the normal social mores of entertaining and visiting' (Willcocks et al, 1987: 151), and consequently,

being the recipient of beverages or food denotes 'outsider' status in the home (Allan, 1989: 154). The extension of such hospitality by staff to guests underlines residents' lack of involvement in formally inviting and accepting visitors and suggests that residents (always recipients of drinks from *staff*), were in some sense perhaps also 'outsiders' in their own home, where staff were entertaining *them*.

COMMUNAL AND PRIVATE SPACE

Receiving support in 'one's own home' usually grants control to the resident, whose 'territory' it is. Staff in residential homes however, often lay claim to offices, toilets and lounges for their own use, their control over the environment reflecting their control over residents' lives (Twigg, 2000: 82-3).

Number 42 occupied ambiguous territory between such a residential institution and the residents 'home' it purported to be. Staff's claims to communal space for work undermined the primacy of the house as 'home' for residents, as did their decisions about admitting outsiders to the home. In other ways too, staff asserted control over communal space. John informed me that the annual Foundation budget had recently allowed the living room and hall to be redecorated, a financial and aesthetic decision that had been taken solely by staff. Control over communal purchases such as freezers, as well as chores reinforce this pattern (Chapter 5). Residents maintained some degree of control over their *private* space, yet this also mirrors how children (and adults living with their parents) may feel about *their* bedroom in a parental home vis a vis communal (parental) space (Marcus, 1997: 160).

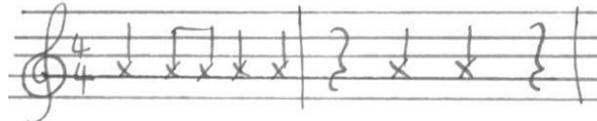
Defining boundaries and managing the use and décor of space are prime exemplars of the 'control over physical and metaphysical space' (Willcocks et al, 1987: 158) which is an essential component of a 'private' home (Allan and Crow, 1989: 3-4). Self-actualisation may even be

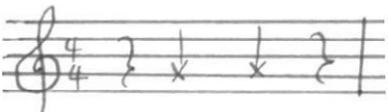
hindered when residents are 'when one person in the family...moulds a place in terms of their own environmental needs and biases, others...may find this place not at all supportive of their self-identity' (Marcus, 1997: 153). I turn now to residents' control of space and access to privacy, examining how in many ways staff appropriation of communal household space is extended also into residents' private domains.

'A ROOM OF ONE'S OWN' : RESIDENTS' PRIVATE SPACES IN THE HOME

Some staff did recognise the need to respect and create private space for residents, for instance through the formalised establishment of systems and agreements. For example I observed this interchange when sitting at the kitchen table:

Chris was drinking coffee at the table. John caught his eye and knocked on the table-



 responded Chris, finishing off the rhythm with two knocks on the table.

'That's our knock, isn't it Chris?' John said, explaining partly for my benefit; 'I do that so you can tell me if its OK to come in, or if you want some privacy, don't I?'

'Yes' said Chris, smiling.

John knocked again on the table and Chris, having just finished his coffee, banged his coffee cup down twice on the table In response, - and laughed. They were both enjoying this, and when John knocked a third time, Chris looked around for a new way to respond. He picked up his wallet and tapped it against his forehead twice, in rhythmic response. Residents, staff and myself laughed.

Although Chris 'lacks words', in this interaction he affirmed his pleasure in his relationship with John, his recognition and enjoyment of the 'secret'

knock and was also able to make a joke. Chris was unlikely to verbally articulate his feelings about privacy, yet when communication was rhythmic, physical, humorous and interactive, he was able to take part in negotiations about his private space. Using such imaginative approaches to communication with learning difficulties can help people with learning difficulties to find a powerful 'voice' (Corbett, 1998).

However, this incident stands in contrast to other occasions, and the attitude of other staff members to residents' privacy. I became quite close to Chris, and on arriving he would often take me by the hand and take me to his room where he would show me his tapes, magazines and other items. On more than one occasion however, staff intervened.

I arrived and Chris immediately invited me into his room. He closed the door and gestured me towards his desk. There were some CDs and DVDs on the desk, some of which I thought were new. 'Did you get these for your birthday?' I asked.

'Yes!' said Chris excitedly, and handed me the ones he had received as presents, for me to look at. Just then, Mark opened the door roughly and jammed the door-stop under it to keep it open. 'Has he kidnapped you already?!' he asked me. 'She's only just got here, Chris!'

Mark may have been reasserting the convention that adult bedrooms are off-limits to 'outsiders' in boundaries of the home (Allan, 1989: 147) and it is certainly likely that he was concerned about the need to guard against abuse. Working with people with learning difficulties means that despite 'fostering independence', staff must remain aware of such risks and *may* have to curtail independent choice. Nevertheless, Chris's power to welcome me as a guest in his own home (and his personal space in it) was usurped by Mark's actions, Chris's control over his private home-space was shown to be subject to limitations and violations. Such issues of control have far-reaching implications: 'the ability to exercise discretion

about who is admitted to one's personal space, whether it is a house, or a bedroom... is not just a question of exercising a right to privacy but it is also about power. The concept of home involves not only the creation and protection of personal space but it also involves profoundly important issues of territoriality and security' (Higgins, 1989: 172). The parental control that the familial idiom suggests legitimises such actions, but they clearly reflect power relations and staff's ultimate control over who is admitted into the home

'HOME DECORATING': RESIDENTS' CONTROL OVER OBJECTS, FURNISHINGS AND DÉCOR IN THE HOUSE

If décor reflects the self and self-history (e.g. Marcus, 1997) residents' private space was notably devoid of such markers and mementoes. While many residents had brought their own items such as videos, electric keyboards, stereos and TVs, larger items of furniture had been supplied by the house. One resident, Chris, was frequently found 'chatting' to inanimate objects in the house, such as the washing machine, the microwave and sometimes the doors. Staff, believing this to be inappropriate, consciously worked to reduce the incidence of such 'behaviour'. Chris's (perhaps unusual) connection to his environmental surroundings may simply be a very clear manifestation of the emotional significance of household objects. This is similar then, to John's eagerness to get home on the day his new couch arrived when John enthused: 'You know how when you've got something new, you just want to get back to it, look at it and touch it and check the stitches and everything'.

Investment in valued objects reflects one's emotional attachment to the living environment. In addition to surrounding oneself with meaningful items, touching, gazing at and even addressing those items may reflect individuals' sense of connection to their home and by extension to their

own history and self-identity which is embedded in household objects and décor (e.g. Marcus, 1997: 61), such items of furniture 'evoke significant memories and affirm individual status and identity' (Willcocks et al, 1987: 151).

A household photo-album provides another (particularly direct) link to history and identity. Photos are a particularly symbolic household object, a compressed autobiography (Marcus, 1997: 239). When I was shown the household's photo album, it was clear that issues in control of space and identity existed. I had been out with some staff and residents for a resident's birthday, where I had also met a former resident of the house (Sylvia), who had moved into a supported living flat a year ago. Back at the house, Mark engaged me in conversation about Sylvia:

'She reminds me a lot of Ben' he said, 'they have the same walk, the same posture. Do you know what I mean? She has the same kind of 'fake smile', when she's anxious and that, or when she's expected to smile' he continued. 'She always does it for photos. I'll show you actually'. Mark left and returned shortly with a photograph album,

'It's a house album really' he explained, 'but we keep it in Bob's room up on the wardrobe to keep it safe- you see what they're like with photos and carrying things around (gesturing to Ben and Chris who were leaving the room)... picking and flicking at them, messing them up...' [Chris and Ben often carry collections of magazines, newspapers and sometimes photographs around the house with them].

Mark and I sat at the table, he turned the pages. There were many pictures of the household over the last few years; former housemates, the kitchen before and as it was being redecorated, younger looking residents celebrating birthdays, doing the cleaning.

'See there it is, the fake smile she does... and that's the garden in the summer, we haven't got out much yet this year... and look, there's Sylvia again- doesn't she have that same posture as Ben?... And see,

there's Bob when he could get about more, he's only started using the walker this last year, he's gone downhill a lot...'

Mark continued to discuss Sylvia and Ben and how Bob's mobility had declined, but I was feeling very awkward since Roy, the house's newest resident was sitting (silently) at the table too. He had moved in 3 months earlier. I asked him 'have you seen these photos of how the house used to look?' 'No' he said. I leaned over to show him one or two. He seemed quite interested. I was very surprised Mark had not given him the opportunity to learn about his new home, its history, its stories and his housemates. Mark didn't take the cue to include Roy at all, and continued to point out peoples' impairments and idiosyncrasies to me.

The control of the photo album illustrated aptly how residents' photographs (and by extension, their shared histories, stories and identity as a household) were a *communal* possession yet were controlled by *staff*. Roy was now a part of the household, but was not a party to the history and explanation that I (though an outsider) was.

Moreover, many photographs were of the house's previous décor and the process of decorating. As such they were particularly symbolic; 'a well decorated home is a symbol of a united family, representing its ongoing collective effort' (Allan and Crow, 1989: 11). Staff's control of the household album mirrored their control of communal space and their control over the household's communal identity.

'PRIVATE LIVES' : THE TRANSPARENCY OF RESIDENTS' LIVES

Like Mark, other staff often attempted to 'explain' residents to me. Jackie, for instance, was keen to show me the residents' 'books' (containing medical, psychological, biographical and behavioural reports) at the kitchen table, (where some residents were also sitting). I felt awkward discussing intimate information about residents while they were

present, and concerned about these ethical/confidentiality issues, I asked whether it was really acceptable for me to see the books. Both staff present seemed to think this a very odd question, and Jackie even seemed offended that I was hesitant about accepting the offered information.

'Privacy' in the home connotes not only physical concealment, but sanctity of one's 'private life'. Habits, histories, and hidden secrets are screened from public viewing and discussion as are *literal* insights into the home (e.g. Twigg, 2000: 80; Allan, 1989: 149). Staff's talk about residents, however, indicated that their lives were not 'private', a 'violation of one's informational preserve regarding self' (Goffman, 1961: 32) which potentially threatens both the self and the home.

Higgins writes that in formal residential care, the bathroom (which is usually the most private place in a home), becomes the most *public* (1989: 168; see also Goffman, 1961: 33). The following incident exemplified this:

In the kitchen, I was chatting to Chris. Ben was wandering in and out with a magazine.

There had been some discussion of Ben's bladder and bowel control problems. On that topic John said to Jackie and Katie, with dramatic emphasis:

'Oh, did you hear about Ben's "little present" he left for me on Sunday?' Jackie and Katie laughed 'Oh he didn't did he? Not again! Where was it?'

'You'll never believe it- all over that wicker chair in his bedroom' Katie and Jackie groaned. 'I couldn't even get it off, it was smeared all through it! I had to just get rid of it, in the end. I dumped it at the tip when I went home'.

The staff discussed this incident in some detail for a while. They seemed to have forgotten, or simply not mind that Chris and I were still there.

Spaces are perhaps constructed by words as much as constituted by physical bounds, and as such bathroom *talk* also exposed some of the most private aspects of residents' lives- locked doors did not mean *discussions* were locked within that context. While for people who lack words, slamming a door may be an eloquent expression of the sense of violated privacy, such *verbal* violations of privacy leave them with little or no 'power of redress' (Stalker, 1998: 12).

Despite my explanations that I was interested in 'the home' generally, staff constantly assumed the focus of my interest to be the residents (and often their impairments and idiosyncrasies). It was seen as legitimate and natural that staff members discuss residents openly with (comparative) strangers. Perhaps because residents are daily 'treated', 'monitored', 'cared for' and 'controlled', it is not surprising they are also readily 'discussed'. Assumptions both of 'what they can understand' and what information was legitimately 'public' property played into such activities, as perhaps did an un-self-conscious informality (staff did not attempt to conceal what they were telling me) echoing parents' talk about children.

'TIME TO (BE) ONESELF' : ROUTINES AND TEMPORAL CONTROL IN THE HOME

Privacy is, then, not always *spatially* located. Autonomy and privacy are also intimately linked to control over time: 'one feature of Total Institutions is that inmates spend their entire lives there under the control of the staff. There are no periods when staff are absent and *it is as hard to establish private time as it is private space*' (Twigg, 2000: 84. Italics mine). Home is thus also a haven temporally, where one can *choose*

when to relax, eat, sleep or do chores (Allan, 1989: 145). The timing of such routine activities is also integral to understanding the home: 'their patterning and the way in which they punctuate the day are central in creating the rhythm and form of domestic life' (Twigg: *ibid*).

Residents' control over time, and over quotidian routines was interesting. On one occasion, Ben had just returned home, come into the kitchen and indicated he would like a drink.

'Can he have a drink?' asked Katie.

'Oh, he's got that new schedule now' John said as he took a folder from the top of the fridge and they consulted it.

John pointed out that 'his 'one-to-one' has written that he had two cartons of juice at ten past three' (it was then 3.30pm).

'Oh that's enough, he shouldn't have anything else yet' said Katie.

'He can have one with his tea' suggested John.

Ben sat at the table, leafing through a magazine. He reached over to my coffee cup and tried to take it.

'That's not yours is it?' Katie chided Ben, and then turned to me, 'You have to watch him, he'll try to drink anything'.

Although such regulation recalls Goffman's descriptions of coercive 'Total Institutions' (1961: 31), Ben's consumption of liquids was regulated because of issues with continence. As noted above, the ideal of fostering independence and allowing a 'dignity of risk' for people with learning difficulties is often contravened by staff's responsibility to ensure that residents remain safe. This sits uneasily with the freedom conventionally associated with 'home'.

Other instances however, indicate that control over routines was not always based in necessity. Staff were complaining to one another about Roy's behaviour and Clare described how she felt Roy was now hostile towards her:

'Me, I'm public enemy number one at the moment!' said Clare. She described how after dinner a few days ago Roy had not taken his plate to the dishwasher. 'Just got up and left it. I asked him to put it away and he said no, cause Chris'll do it! And now he's not talking to me' Linda seemed shocked. Jackie concurred that Roy was often neglectful about tidying up.

Clare continued 'I mean, Chris *will* pick it up, but I told him- Chris doesn't *have* to, he just does it 'cause he's nice. I said- it's *your* plate, *you* have to put it away'.

After some more complaints about Roy neglecting tasks (which seemed to imply some difficulties in the house), I asked 'Do you think he's settling in all right?'

'Yeh, he's just a bit moody' said Clare.

In light of the 'supported living' ethos at Number 42, it seemed incongruous that Roy's choice to leave a plate on the table in *his home* was so contested. Moreover, his tacit understanding that Chris would clear up (which Chris seemed happy with) was overruled by the staff. It was not Roy or Chris who could decide how the house was run and tidied, but staff. Again, issues regarding household activities and communal space were in the hands of staff.

'WHOSE HOME IS IT ANYWAY?': SOME CONCLUSIONS

Staff's control over communal space and over the definitions and management of boundaries around the house accords with the parental model I outlined previously. Residents' limited control over such matters echoes that of children in a family home.

Staff (and their work) dominated communal space and sometimes penetrated into residents' private spaces, private lives and private time. Although the parental idiom can explain staff's control over the home and home life, other structures of power cannot be ignored. Residents, with

learning difficulties and limited verbal communication are certainly less powerful in society than articulate staff working within a formalised structure of 'care-giving'. 'Control' is, however, a complex issue when people are vulnerable or whose 'intellectual impairments' impact their social and decision-making skills.

Nevertheless, the management and meaning of home for people with learning difficulties is heavily influenced and moulded by staff's exercise of control over space, privacy, talk, objects and time in the home, and although the family idiom may somewhat 'normalise' the home, the 'normal' privacy of the home is often lacking.

**'FINDING THE WAY HOME':
CONCLUSIONS AND DIRECTIONS**

OUTLINE

In drawing together this research, I will summarise how the ideas of family, and of privacy and control which I have explored, impact the meaning of home in Number 42. Since the ideal of 'home' and the everyday experience of home for participants in this study seem so discrepant, I will examine why this is so, and what potential exists for redressing the situation in homes such as this.

THE MEANING OF HOME IN NUMBER 42

I have illustrated how the experience of 'home' for people with learning difficulties at Number 42 was frequently far from the ideal and normative 'home' that literature on the 'meaning of home' has depicted. In many ways, normative understandings of 'home' *did* impact the construction and understanding of 'home' in Number 42. The association between 'home' and 'family' was a potent example. The model of the 'family home' certainly influenced and shaped staff's and residents' understanding of their roles in the house (specifically as 'parents and children' in that household). 'Family homes' also provided a point of contrast in the negotiation of Number 42's status as a 'home'. However, the house also lacked the intimacy, informality and unity of a real family home, and other homes often made a significant claim on emotional and temporal resources. In summary, although the 'family' was a useful concept for participants in making sense of Number 42, the disparities between real family life and life in this house ultimately exposed the

untenability and inauthenticity of the 'family model'. The house was clearly not a 'family home', yet use of the 'family model' *also* undermined its legitimacy as a 'supported living' house for adults, since the 'family model' framed adult residents as dependent children. For residents, the home therefore offered neither the *security* of a family home nor the *independence* of an adult home.

Likewise, consideration of issues of privacy, boundaries and autonomy in Chapter 6 illustrated the ambiguous nature of Number 42 as a 'home'. For example, staff exerted control over the admittance of 'outsiders' to the house and made significant claims on communal space for their paperwork. This control of communal space reflects the 'parental idiom' (outlined above), since children exert power only over their personal spaces (bedrooms). Residents did have autonomy and privacy in their own rooms and over their own items, yet this was often challenged by staff. Furthermore, residents' *lives* were accorded little privacy, and staff often controlled routines, daily activities and chores within the home. In summary, the autonomy, privacy, control and opportunity for self-expression in the home which are conventionally understood as *defining features* of home were largely unavailable to the residents of Number 42.

The inconsistencies between normative homes and life in Number 42 must be understood with relation to the power dynamics between staff and (disabled) residents. As proponents of the social model of disability have observed, the construction of dependency (Barnes, 1990); the infantilisation of disabled people and the denial of autonomy are ways in which service provision 'disables' people with impairments. In some instances, disparities in verbal articulacy also enabled staff to 'disable' residents, for instance when staff discussed residents' personal lives publicly.

Residents and staff drew on the ideology of *home* to navigate the house, yet through the relations of power (above), the house also echoed patterns found in *institutions*. Number 42 was situated between 'home' and 'not-home': participants used, referenced, and appropriated *elements* of the concepts of 'home', 'institution', 'workplace' as they made sense of and negotiated the shared space. It was, in effect, a home that was not quite 'at home' with itself.

FINDING NEW HOMES

Although this study outlines only some of the aspects of the meaning of home in one particular house, many questions arise for considering the meaning of home for people with learning difficulties more generally: Must life in staffed homes inevitably fall short of the conventional experience and meaning of home? Can people with learning difficulties in shared, staffed houses meaningfully establish those houses as their 'homes'? How does the experience of people with learning difficulties in other types of housing offer insights into the construction of 'home'? Is an 'independent home' incompatible with the physical, social and intellectual support some people with learning difficulties require?

Tentatively, I would suggest that the 'family model' is often likely to impact on the understanding of staffed homes. However, there is potential for staffed homes to recognise this and utilise the positive aspects of the 'familial model', such as intimacy, warmth and acceptance while minimising the more dubious 'parent-child' relationships that I have outlined (see also Twigg, 2000: ch 8).

Alternatively, perhaps assumptions underlying the concept of 'home' could be explicitly addressed by service providers. The 'family model' (and the oppressive 'institutional' model) offer staff and residents ways of

understanding the home in the absence of any other blueprint. However, perhaps other 'models' could be formulated which reflected and explored the unique and unconventional character of staffed, shared homes while also recognising the socially valued aspects of 'home', thereby reducing the need to model relationships and practises on familial or institutional living.

Ultimately, however, the control staff exert over space and the readiness with which the parental model can be adopted reflects prevalent notions about the need and desirability of controlling (and 'looking after') people with learning difficulties. Addressing such attitudes is a much bigger project in dismantling 'disabling barriers', and this study has merely touched the surface of these concerns. Nevertheless, I would hope that exposing and discussing the dynamics in the construction of 'home' contributes to the questioning and analysis of the experience (and oppression) of people with learning difficulties. Failing to question the nature and meaning of 'home' denies the complexity of homes; the degree to which they are created and negotiated by their participants; and their profound impact on the self as well as what these processes can show us about both 'conventional' and 'unconventional' homes and the dynamics of the society in which we live.

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