

PEOPLE WITH LEARNING DISABILITIES AND THE CONSTRUCTION OF  
INTERPERSONAL RELATIONSHIPS

Ruth Danielle Wilson

Submitted in accordance with the requirements for the degree of  
Doctor of Clinical Psychology (D. Clin. Psychol.)  
The University of Leeds  
Academic Unit of Psychiatry and Behavioural Sciences  
School of Medicine

July 2007

The candidate confirms that the work submitted is his/her own and that appropriate credit has been given where reference has been made to the work of others.

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

## ACKNOWLEDGEMENTS

A number of people made valuable contributions to this piece of work:

First and foremost I would like to thank the participants who gave their time, and shared their wisdom, thoughts and experiences with me. This piece of work would not have been possible without you.

Thanks also to Tom, Carol and Lorna, who provided much valued academic support but who also demonstrated enthusiasm in the topic and a belief that I could fulfil the task. You helped me to keep going at times when I was unsure I could meet the challenges I faced.

Last but not least, thanks to Kev, for sharing in the highs and the lows of the past two and a half years with patience and understanding.

## ABSTRACT

Interpersonal relationships play an important role in our sense of self and satisfaction with our lives. Literature suggests that people who have learning disabilities have limited opportunities to make and maintain interpersonal relationships; however few studies have questioned how this situation has developed and how it may be maintained. In addition much research has largely excluded first-hand accounts of people who have learning disabilities.

In this study I interviewed staff and service-users at a centre which provided day services to people with learning disabilities, about interpersonal relationships. I analysed the data using discourse analysis. Drawing on this data I argue that dominant discourses which view people who have learning disabilities as being 'childlike' and/or qualitatively different to those who do not have learning disabilities, supported constructions of relationships that worked to limit the power and opportunities of service-users. These constructions were influenced by historical ideas about relationships and about people who have learning disabilities, which continue to influence service-provision through social and political pressures. Participants also however drew on alternative discourses, and alternative ways in which relationships could be constructed. These constructions emphasised reciprocity and enabled service-users to engage in relationships in which power was more equally distributed. The existence of these alternatives offers hope for a different way of understanding relationships, where one or more person has a learning disability.

I discuss these findings with reference to the wider literature and argue that learning disability services must engage in a process of critically questioning taken-for-granted 'truths', if they are to circumvent the influence of disempowering discourses and open up opportunities for more empowering practices.

## TABLE OF CONTENTS

ACKNOWLEDGEMENTS .....	2
ABSTRACT.....	3
TABLE OF CONTENTS.....	4
LIST OF TABLES .....	6
LIST OF FIGURES .....	7
CHAPTER 1: INTRODUCTION .....	8
1 Preamble .....	8
2 Terminology.....	8
3 Relationships and People with LD .....	9
4 Quality of Life Research.....	24
5 History, Language, Meaning and Learning Disability .....	25
6 Concluding Comments .....	29
CHAPTER 2: METHOD.....	31
1 Theoretical Methodology.....	31
2 Ethical Issues .....	37
3 The Service.....	41
4 Recruitment .....	42
5 Interviewing.....	44
6 Method of Analysis.....	47
7 Research Diary .....	50
8 Quality of the Research .....	52
9 Writing Up .....	53
CHAPTER 3: ANALYSIS .....	54
1 Discursive Constructions.....	55
2 Discourses .....	72
3 Action Orientation .....	79
4 Positioning.....	87
5 Practice.....	92
6 Subjectivity .....	99
7 Institutions, Power and Ideological Effects .....	101
8 Concluding Comments .....	104
CHAPTER 4: DISCUSSION .....	105
1 People who have Learning Disabilities and Interpersonal Relationships.....	105
2 The findings of this Study within the wider context .....	115
3 Implications for Practice .....	122
4 Strengths, Limitations and Implications for Future Research .....	124
5 Conclusions .....	127
6 Personal Reflections .....	128
BIBLIOGRAPHY .....	130
APPENDICES .....	147



<b>Appendix 1:</b>	<b>Letter of Ethical Approval from Harrogate Local Research Ethics Committee.....</b>	<b>148</b>
<b>Appendix 2:</b>	<b>Project Poster .....</b>	<b>149</b>
<b>Appendix 3:</b>	<b>Service-User and Staff-Member Interview Information Sheets.....</b>	<b>151</b>
<b>Appendix 4:</b>	<b>Service-User and Staff-Member Consent Forms .....</b>	<b>155</b>
<b>Appendix 5:</b>	<b>Transcriber Confidentiality Form.....</b>	<b>157</b>
<b>Appendix 6:</b>	<b>Interview Topic Guides .....</b>	<b>158</b>
<b>Appendix 7:</b>	<b>Interview Transcript Extract and Worked Example of Analysis .....</b>	<b>163</b>
<b>Appendix 8:</b>	<b>Extract of Observational Data and Worked Example of Analysis .....</b>	<b>169</b>
<b>Appendix 9:</b>	<b>Literature Search Strategy.....</b>	<b>173</b>

## LIST OF TABLES

Table 1: Service-User Interview Outline .....	45
Table 2: Staff-Member Interview Outline .....	46
Table 3: Transcription Conventions .....	47
Table 4: Stages of Analysis - Linguistic Data .....	48
Table 5: Stages of Analysis - Visual Data .....	50

**LIST OF FIGURES**

**Figure 1: The Day Service Symbol..... 61**

## CHAPTER 1: INTRODUCTION

### *1 Preamble*

I began this research during my first year of clinical psychology training. At this time I was asked to undertake a piece of doctorate level, clinically relevant research as part of my training. I found it hard to make the decision about what to research, and how I would undertake the research. In order to make my decision I found myself reflecting on my pre-training work experience, and thinking about what new understandings I might bring to bear on this experience, by applying some of the new ways of thinking that I was being exposed to as part of my training. Prior to undertaking clinical psychology training I had worked as an assistant psychologist in an NHS forensic learning disability service, before accepting a post as a research assistant working on a project which explored assessment of risk in the field of learning disability. When I looked back at this experience I was struck by how much of my work had focused on intrapersonal factors, and wondered what might be gained by exploring the interpersonal worlds of people who have learning disabilities (LD). After some discussions with clinical psychologists who worked locally in learning disability services, I decided to explore how interpersonal relationships were constructed by and for, people who had LD, and with what effects. The current study offers an account of that exploration.

### *2 Terminology*

Before reviewing the relevant literature, I would first like to make some comment on the terms that are used variably to refer to the group of people in question. I have chosen to refer to people who have ‘learning disabilities’ (LD) in my review of the literature. This is the term most widely used by services in England. Other labels are used in other places and other settings, for example ‘mental retardation’, ‘intellectual disabilities’ and ‘developmental disabilities’ are other labels that are sometimes applied to this group of people. People First (an international advocacy organisation) prefers the term ‘learning difficulties’ however within the UK this

term is often used to describe problems in learning that children may demonstrate as a result of a number of different things including medical and/or emotional problems, and so it may be misleading. There is some literature which suggests that whatever label is chosen, it has little meaning for the people to whom it is applied, and that it might only be meaningful in relation to the organisation of services (Finlay and Lyons, 2005). The term 'service-users' is sometimes used by people who have received or are receiving services of some kind. The people who attend the centre in which this research was based consider themselves to be 'service-users' therefore this is the term I have chosen to use in any reference to this specific group of people.

This research is concerned with interpersonal relationships which hereafter will be referred to simply as 'relationships'. Such relationships represent the social bonds that exist between two or more people, and which result in interaction.

### **3      *Relationships and People with LD***

Historically, much of the literature relating to people with LD and interpersonal relationships has been concerned with perceived deficits and corrective interventions. In this section I shall look at literature which has considered relationships as social inclusion, relationships as friendship, intimate/sexual relationships, parenthood and familial relationships. I then consider the various constraints upon relationships that people who have LD might experience.

#### **3.1      *Social Inclusion***

Since the advent of community care for people with LD and the adoption of philosophies such as social role valorisation, the importance of social interaction has been increasingly recognised. The white paper 'Valuing People' (Department of Health, 2001), recognises that people who have LD are often socially isolated, and recommends that services help people to develop opportunities to form relationships. Accordingly, there has been a focus on social interaction interventions, which

emphasise participation in typical environments, with typical peers, and engaging in typical activities (Kennedy, 2001). Despite initiatives to maximise inclusion however, the literature reviewed here suggests that people who have LD have fewer social contacts and fewer social relationships than community members who do not have LD.

It has been suggested that people who have LD who live in the family home may have smaller social networks and fewer community contacts than those who live in residential settings (Krauss and Erickson, 1988). Meanwhile, studies exploring the social interactions of people with LD living in residential settings suggest that for many individuals, activities undertaken in the community tend to be supervised by staff and occur in groups with other disabled peers (e.g. Ashman and Suttie, 1996; Lord and Pedlar, 1991; Ralph and Usher, 1995). This raises questions about the extent to which such interactions reflect 'real' integration.

One means of promoting social inclusion has been initiatives which enable people who have LD to gain employment alongside non-disabled colleagues. Studies by Butterworth and Strauch (1994) and Ohtake and Chadsey (1999) indicate that most relationships developed within work placements where the majority of colleagues do not have LD, are restricted to the work setting and social friendships characterised by colleagues meeting as friends outside the work setting are rare. Chadsey and Beyer (2001) review literature regarding intervention strategies which promote social relationships within the workplace between people who have LD and those who do not. They attribute the difficulty in achieving inclusion to the social difficulties that people who have LD experience, and specifically note that there may be a difference in interactions and/or ability to converse for such individuals. In order to promote inclusions they recommend 'teaching' appropriate behaviours to workers who have LD and utilising services and resources that are typically available in work settings. These studies are influenced by philosophies of normalisation, and thus are concerned with individual ability and functioning as



compared to 'normative' standards. They pay little attention to social structure and power differences that may prevent the realisation of goals.

Difficulty in achieving the goals of social inclusion may be attributed at least in part to the negative attitudes that people who are not labelled as having LD hold towards those who do. Gordon, Tantillo, Feldman and Perrone (2004) surveyed undergraduate psychology students about their attitudes towards interpersonal relationships with people who were diagnosed with an illness or disability. They found that participants reported particularly negative attitudes towards people who had a mental illness or LD. Furthermore, respondents reported that they were least likely to want to be friends with, or marry a person who had LD, as compared to somebody who had a diagnosis of some other disability or illness. No commentary is offered on the origins of such attitudes, and it is unclear whether the results might be generalised outside of their largely homogenous sample. The study does however highlight the attitudinal barriers that people who have LD might encounter when they interact with people who do not have LD. One of the reasons that people with LD might experience stigma and discrimination, is that in western countries at least there is an emphasis on independence and the 'self-contained individual' (Gregg and Phillips, 1996). Stigma and discrimination towards people with LD however is also prevalent in non-western countries. Pearson, Wong and Pierini (2002) for example note that 'average' citizens in a Chinese town were reluctant to accept people with LD in the community, and did not treat them with respect as equals either in the workplace or in other locations. The authors note that in Chinese society young people achieve recognition of their transition to adulthood through work and contributing to family income.

Despite the popularity of social inclusion interventions, there is some emerging discontent, with criticism levelled at the perceived 'denial of disability' and a lack of appreciation of the value and meanings that relationships with other people who also have a LD may hold. Reinders (2002) has proposed that it is not citizenship but friendship that matters.

### 3.2 Friendships

Studies indicate that people with LD have few opportunities to make and maintain relationships with friends. Krauss, Seltzer and Goodman (1992) found that almost half of a sample of adults with LD living in the family home, had no friends who were not family members, and only a quarter of the sample reported having at least one friend who was independent of their mothers' friendship networks. Le Touze and Pahl (1992) surveyed people who had LD living in two local authority areas about their satisfaction with service provision. Their results indicated that participants felt most dissatisfied about their social relationships. In particular, participants reported that they desired more friends, and that service-providers did not afford relationships high priority. Dudley (2005) reported that from a sample of participants dually diagnosed with mental illness and mental retardation, 30% identified a staff member as their best friend, and that whilst participants often indicated that the friendship was mutual, the staff members involved usually did not agree. In the Australian National Consumer Satisfaction Survey, 32% of respondents living in larger accommodation services reported that they had no friends, and only 24% of participants who reported having a friend could claim a friend who was neither a family member nor a paid worker (Steering Committee for the Review of Commonwealth/State Service Provision & National Disability Administrators, 2000).

The median size of the friendship networks of people with LD (excluding staff) may be as few as two people (Robertson, Emerson, Gregory, Hatton, Kessissoglou, Hallam et al., 2001). A further study investigated the frequency of friendship activities for a sample of people who had LD. Over a four week period, the median number of occurrences of friendship activities with friends who also had LD was 2, whilst the median number of friendship activities with friends who did not have LD was 0 (Emerson and McVilly, 2004). Crapps and Stoneman (1989) surveyed individuals who cared for people who had LD in their homes. Their results indicated that most home providers reported that residents had more than four friends (some of whom had LD and some of whom did not), however a high

proportion of residents had had little or no recent contact with friends. The data did not allow any discrimination between which friends were also friends of the home provider, and it may be that the results reflected social desirability of responding with home providers wishing to be seen to be providing high quality placements.

It has been suggested that certain conditions are required in order for a person to be able to make and maintain friendships. Richardson and Ritchie (1989) suggest that those conditions are opportunities and abilities, whilst Firth and Rapley (1990) emphasise motivation, opportunity, confidence and skill. Accordingly, interventions aimed at promoting friendship have tended to look at either increasing the number of opportunities that people with LD have to meet people and socialise, or to promote an individual's skills in social interaction. Moore (2005) reviews literature on skills development. She suggests that traditional social skills approaches are limited in the extent to which those skills are generalised to other settings, but suggests that peer mediated approaches (which operate in a natural environment and utilise positive feedback from peers) might offer a more effective alternative. Interventions which aim at increasing skills however might reinforce conceptions of LD which are based on deficit and deviation from a cultural 'norm'. Such interventions limit opportunities for a more critical reflection on the social barriers to friendship formation. Befriending services have been used as a means of increasing social contacts for people who have LD, and thus as a means of increasing opportunities for friendship formation. Befriending relationships are distinct from friendships however in that the former is a service whilst the latter is a private, mutual relationship. Heslop (2005), interviewed workers from seven befriending schemes, a sample of adults with LD who had experience of being 'befriended', and the families of children who used the schemes. The study noted positive and negative opinions about the services but found that breaks and endings in the relationship were often particularly problematic, with many befriended reporting feelings of confusion, sadness, anger and disappointment in relation to the ending of a befriending relationship. Advances in technology have led to increased opportunities to develop and maintain relationships with others. Seale and Pockney



(2002) explored the extent to which people with Down's Syndrome used web-based Personal Home Pages as a tool to make contact with friends and to manage identity. Of 20 pages that they identified, 16 made some reference to friendship and supported the construction of an identity that emphasised the individual's capability of making and maintaining friendships.

Much of the literature relating to friendship and people who have LD has utilised quantitative methods and relied on numerical and pre-defined categorical data. Such data can tell us something about the number of friends participants report having and the types, frequencies and locations of friendship activities; however they permit little commentary on the subjective experience of friendship for people with LD. Knox and Hickson (2001) interviewed four people with LD about relationships which they described as being close friendships. Friendships with a person considered to be a 'good mate' were characterised by: the friend being important and playing a pivotal role in participants' lives; the friend playing a pervasive part in participants' lives; a shared sense of history; opportunities to share common interests; and, friends being a reliable but reciprocal source of support to participants. These relationships appeared to be maintained by the mutual negotiation of arrangements to meet and do things together as friends, by balancing the needs of the relationship against other relationships, and by remembering and reminiscing about shared experiences. All four participants identified only other people with LD as being people with whom they had a close relationship. Day and Harry (1999) utilised an ethnographic case-study approach to explore the construction of a friendship between two adolescent girls who had LD. Their work indicated that the friendship that developed between the two students was spontaneous and based on: mutual liking, enjoyment and benefit; similarity of age and interests; and, intimacy. In this respect the relationship reflected the characteristics considered to be 'typical' of friendships that develop between people who do not have LD. Disability did not limit the quality of relationship; in fact the authors argue that it may have enhanced it through mutual understanding and empathy. These latter studies emphasise the meaningfulness of relationships that

exist between people who have LD. Chappell (1994) argues that a distinction must be made between situations when people who have disabilities *choose* to be together on their own terms and situations where they are together on terms *not* of their own choosing. Furthermore Szivos (1992) has argued that initiatives aimed at integration encourage people who have a learning disability to disaffiliate from their peer group, and disregard the meaning and value of friendships between people who have LD.

Despite the acknowledgement in the literature that people who have LD may have limited opportunities to develop friendships, the lack of commentary on how this situation has developed and been perpetuated, is noticeably absent.

### **3.3 Intimate/Sexual Relationships**

Historically, people with LD have been denied the rights and opportunities to sexual relationships that have been afforded to other members of the population. Segregation and institutionalization meant that people with LD had limited opportunities to develop sexual relationships; sexual behaviour was often punished and enforced sterilisation was not uncommon. Most people who have LD now live in the community and as such many of the physical barriers to engaging in a sexual relationship have been removed. The literature reviewed here however suggests that attitudes regarding the sexual rights and needs of people with LD may effectively limit opportunities for such relationships.

People who have LD may face negativity and/or ambivalence with regards to their sexual rights and needs. Aunos and Feldman (2002) reviewed articles pertaining to attitudes towards sexuality, sterilization, marriage, procreation and parenting by people with LD. They noted that a majority of direct-care workers accepted certain sexual behaviours like masturbation, hugging and brief kissing in people with LD but that disapproval increased the greater the degree of intimacy of sexual contact and that in general, direct-care staff thought that people with LD should be discouraged from having sexual relations. The studies reviewed also indicated that

parents of children with LD held ambivalent or restrictive attitudes, and avoided talking about sex with their children. Murray, MacDonald, Brown and Levenson (1999) surveyed employees of statutory, private and voluntary organisations which provided services to individuals with LD, about attitudes towards the sexuality of service-users. They found that moderate to highly liberal attitudes towards client sexuality were reported by most participants, with health-care, management and professional staff reporting significantly more liberal attitudes than direct-care staff. Sampling issues however may have discouraged the self-selection of participants who held more conservative attitudes. Though these studies offer some insight into attitudes towards people who have LD engaging in sexual relationships, they do not offer any exploration of how such attitudes influence practice.

Löfgren-Mårtenson (2004) noted that staff and relatives who cared for people with LD encouraged friendships over sexual relationships. Intimate relationships that did evolve were subject to a high level of supervision and the quality and expressions of the relationship were often judged by others. It was also noted that sexual intercourse was quite uncommon amongst learning disabled youths and that this may have been a consequence of a restrictive attitude towards intercourse, held by staff and/or parents.

Some studies indicate that people with LD themselves reported negative attitudes towards sexuality, for example Lesseliers (1999) interviewed people with LD about their perceptions of relationships and sexuality and found that of participants who had had sexual intercourse approximately half reported ambivalent or negative feelings about their experience. Participants described physical feelings and behaviours that they associated with being in love, though most described intimate activity with a partner that went no further than caressing, kissing, cuddling and hugging. A small number of participants expressed a desire to take things further, but indicated that opportunities to do so were limited.



The literature also suggests that people who have LD hold romanticised views of intimate relationships that emphasise love, romance, monogamy and heterosexuality. Löfgren-Mårtenson (2004) noted an internalised 'love ideology' amongst young people with LD who believed that it was preferable for sexual activity to occur within a relationship where two people are in love. Similarly, Knox and Hickson (2001) reported that participants' accounts of intimate relationships appeared to be characterised by: the relationship being different to other close relationships; by feelings of intimacy; by being physically attracted to the other person; and, by an expectation of relationship change e.g. through marriage. In Lessliers' (1999) study all participants who reported finding sex pleasurable were reported to be in a long-term loving and stable relationship. There was no report of consenting sexual activity that did not take place within the context of being 'in love'. A romanticised view of relationships was also noted by White and Barnitt (2000). They interviewed people with LD about intimate relationships and reported that all participants who were currently in a relationship indicated that the relationship was heterosexual, that they believed they would stay together forever, and that they had contemplated marriage. In addition though some participants commented on negative experiences of relationships none of these related to the individual's current relationship.

Past experiences of relationships may inform the development of current and future relationships. Scior (2003) interviewed women who had LD in order to explore how they positioned themselves with respect to gender and disability. Though romantic discourses of love and marriage were employed, past relationships were also described which involved instances of exploitation and abuse. It was noted that women held low expectations for themselves and described little sense of entitlement to relationships that were built on equality and respect. McCarthy (1993) interviewed women who had LD about their sexual experiences and found that sex was generally considered to be for men's pleasure at the expense of their own. McCarthy argued that participants' sexuality was inextricably linked to men and so they had no means of understanding any sexual feelings that did not conform to that context (such as sexual activity with other women or masturbation). The

findings reflect differences in power that reside in gender relations and which many women who do not have LD also experience; however women who have LD may have less access to information and support which would help them to challenge the situation.

A study by Thompson (1994) points to a lack of mutuality in the sexual experiences of men with LD who have sex with other men. Few of the men interviewed described their experiences of sexual contact with other men as being positive, and there was little evidence of participants exercising choice and/or control over their sexual activities. Work aimed at promoting safe sex practices was judged to be ineffective, and this was attributed in part to participants' low self-worth. It was argued that participants' sexual contacts placed them at risk of contracting HIV and that in some cases it would be appropriate for services to intervene to reduce this risk, for example by increasing supervision and/or limiting participants' opportunities for sexual contact with other men (particularly those who did not have LD). Cambridge and Mellan (2000) however argue that research and practice in sexuality and LD has pathologised the sexual behaviour of men with LD with damaging consequences. They argue that there has been a particular focus on the abuse and exploitation of women who have LD, and of high HIV risk sexual behaviour with men who do not have LD. In addition they suggest that practices such as the use of pornography, cross-dressing, prostitution and stylised sexual practices are pathologised to a greater extent than may be the case in the general population. A tendency to attribute a sexual motive to interactions with children was also noted. The authors argue that the effect of this focus has been to neglect wider issues of sexuality and sexual needs.

Brown (1994) suggests that LD services have an implicit role in the regulation of sexuality and the creation of sexual boundaries; but argues that there is a cultural differential with regard to what constitutes sexually 'appropriate' behaviour for people who have LD, as opposed to those who do not. Furthermore Brown argues that LD service structures limit opportunities for sexual experiences and that where

sexual relationships involving a person who has LD do develop such relationships are controlled and desexualised through the imposition of 'romantic' expectations. The unwillingness of services to acknowledge and support other forms of relationships limits their consideration as viable alternatives for people who have LD.

The continuing influence of philosophies of 'normalisation' in determining the goals and practices of LD services may account in part for the dominance of the 'romantic' discourse in literature regarding the sexuality of people who have LD (Brown, 1994). For example, Wolfensberger and Glenn (1975) advocated that services support "*heterosexual socialization activities*" and develop support systems to help people with LD live "*married lives*" (p.75), whilst Wolfensberger and Thomas (1983) recommended that services encourage heterosexual dating behaviour. Furthermore the cultural construction of sexual intercourse as a natural biological instinct aimed at procreation further privileges heterosexual relationships and obscures the role that social forces play in shaping sexuality (Weeks, 1989).

### **3.4 Parenting**

The literature presented thus far suggests that people who have LD are often prevented or discouraged from entering into sexual relationships. One of the reasons for this is that their families, carers and/or professionals who work with them might have concerns about such a relationship resulting in pregnancy. Stansfield, Holland and Clare (2007), reviewed case study notes of legal applications to perform sterilisations on people said to lack capacity, between 1988 and 1999, in the UK and Wales. Of 73 applications all but one was made in relation to a person who had LD, and of the 39 that proceeded to a court hearing, in 31 of the cases it was ruled that sterilisation was in the person's 'best interests'. Aunos and Feldman (2002) noted that studies conducted in the 1970's found that up to 80% of parents and care staff favoured the sterilization of people with LD as a method of birth control. Whilst Wolfe (1997) indicated that such attitudes were prevalent amongst teachers and



school administrators particularly in relation to people with more severe LD. The findings of these studies resonate with ideas espoused by eugenics movements in the late nineteenth and early twentieth century.

With regard to marriage and parenting, Aunos and Feldman (2002) reported that approximately 75% of parents were against their children marrying and raising children of their own. Care workers and professionals also maintained major concerns about these issues. In contrast, 60-90% of people with LD expressed a desire to marry and raise children. Löfgren-Mårtenson (2004) noted ambivalent feelings amongst staff members and relatives with regard to sexuality and young people with LD, and that there was a particular fear of sexual relationships resulting in pregnancy. Staff members and carers expressed a sense of responsibility to prevent this happening. It was noted that few youths with LD envisaged a future in which they would have children and a family of their own.

Little research has explored the experience of parenting from the perspective of the parent who has LD, though Booth and Booth (2006) present narratives of parents who have LD who are involved in care proceedings. The accounts suggest that the experience is fraught with anxiety, frustration and powerlessness as parents are subject to intrusive interventions which appear to them to be arbitrary and unfair. Llewellyn (1995) used a grounded theory methodology to explore the views of parents who had LD, about their relationships and support. The results indicated that partners, family and/or professionals were sources of support. Support from one's partner tended to be most valued, whilst professional support was generally sought by parents after other avenues had been explored or in emergency or novel situations. The majority of the parents in the study did not have any friends that they could seek support from and none had any friends who were also parents with LD.

The parent-child relationship is one which is highly valued in society and it is pertinent therefore to question what barriers must be overcome, before people who

have LD are afforded the same rights and responsibilities of parenthood, that most others take for granted.

### **3.5 Familial Relationships**

A large number of people who have LD continue to live with their families well into their adulthood (Evans, Todd, Beyer, Felce and Perry, 1994; Seltzer, 1992). Some of the literature already presented suggests that parents have an influential role in the extent to which people who have LD are facilitated or constrained in their interpersonal relationships. This will not be elaborated further; instead I will consider aspects of the parent-child relationship where the child is an adult who had LD. Literature suggests that parents of adults who have LD view their children as being vulnerable and are reluctant to enable them to take risks because of a wish to protect them (McConkey and Smyth, 2003). Parents may be particularly concerned about their adult offspring's vulnerability to sexual abuse (McConkey and Smyth, 2003, Heywood and Huckle, 1995). Concerns about vulnerability may not be entirely unwarranted. A review of research by Horner-Johnson and Drum (2006) suggested that people who have LD are more likely to experience maltreatment than people who do not have disabilities, and that people who have LD may experience more maltreatment than people who have other forms of disability.

Literature that explores parental responses to discovering that their child has LD, suggest that this experience is characterised by pain and sorrow (e.g. Cunningham and Davis, 1985) however Vetere (1993) suggests that these painful emotions may be re-experienced later in life, when culturally expected transitions (such as leaving home or marriage) do not occur and parents are again confronted with the realisation that their child is 'different' to others who do not have LD. Such literature supports ideas that equate disability with tragedy and loss. Todd and Shearn (1996) differentiated between 'captive parents' who found it difficult to live an 'ordinary' life and experienced a sense of loss associated with this, and 'captivated parents' whose identity was inextricably bound up with their continuing parenting role and

for whom the loss of this role would provoke a crisis of self. Such research supports constructions of relationships in which the person who has LD continues to be dependent upon their parents for support. Walmsley (1993) however argues that for some adults who have LD and who live with aging parents, caring may be reciprocated. For example the person who has LD may provide physical care for their parents, whilst still depending on them for tasks which require numeracy or literacy (for example). She argues that for some families caring may be more usefully conceived of as interdependency.

### **3.6 Constraints on relationships**

The vast majority of the literature reviewed here, points to the power that parents, carers, service providers and health professionals have in order to enable or constrain the development of relationships for people with LD. For example Knox and Hickson (2001) highlighted the importance of having time alone with a close friend, in order for relationships to be enacted, along with the difficulty of achieving this within an institutional setting. The importance of setting factors as opposed to personal characteristics in accounting for variation in level of friendship activities, was also highlighted by Emerson and McVilly (2004), who suggested that promotion of relationships and support for people with LD be achieved at a systems level rather than through interventions aimed simply at the individual development of social skills. Meanwhile, Ashman and Suttie (1996) noted that the restricted opportunities to engage in community activities reported in their sample, reflected to some degree limited choice and opportunities for decision-making. Day and Harry (1999) observed that disability influenced a number of barriers to the further development of the friendship they explored in their study. Those barriers reflected logistical concerns (in relation to access and transport), cultural attitudes towards young women in the family, and parental concerns about the girls' vulnerabilities. Heslop (2005) noted that befriendees would have liked to have had more influence over the frequency of contact and the choice of activities that were undertaken within the befriending relationship.



In her study on sexuality, Löfgren-Mårtenson (2004), pointed out that the leisure time experienced by most young people with LD was often restricted and characterised by strict boundaries, it was difficult to know where and whether sexual exploration was allowed. Lesseliers (1999) reported that "*the circumstances of people's lives shape their perceptions of sexuality and relationships*" (p.137). White and Barnitt (2000) reported that some participants in their study described negative views and actions from parents and carers with regard to their relationships, for example some participants reported having little privacy, or that others became 'too involved' in their relationships. Scior (2003) identified a 'guardianship discourse' within her study with participants occupying a dependent role where choice and control was limited and people with LD were viewed as being vulnerable and in need of protection.

In relation to parenting Llewellyn (1995) reported that some parents found that family members could be unhelpful, constraining and intrusive in their actions, whilst the intervention of professionals sometimes ignored parents' difficulties in understanding and learning new concepts, or conflicted with advice they had been previously given. Booth and Booth (1993) suggested a need for a user-centred framework to guide the intervention of professionals working with parents who have LD. They argued that such a framework would enhance parents' sense of control and would promote an experience of professional support that was augmentative rather than limiting.

The literature presented here suggests that people who have LD have limited power, choice and control in their interpersonal relationships. It is argued here that these forms of action and experience are the result of particular constructions of relationships and of people who have LD, thus it is pertinent to explore what those constructions are, how they have developed, and how they are maintained.

#### 4 *Quality of Life Research*

There is an increasing impetus for learning disability services to demonstrate that the services they offer are of high quality and that the people in receipt of those services have an acceptable 'quality of life' (QOL). The use of QOL as a means of evaluating services has led to efforts to operationalise the construct, thus there has been an emphasis on properties and attributes which are measurable. Verdugo, Schalock, Keith and Stancliffe (2005) suggest that the measurement of QOL is characterised by: its multi-dimensional nature involving core domains and indicators; the use of both objective and subjective measures; a consideration of how personal characteristics and environmental variables relate to QOL; the incorporation of a systems perspective that captures QOL across multiple environments; and, the involvement of people with LD in the design and implementation of QOL initiatives. It has been said that QOL "*provides an ongoing framework to promote well-being at the personal, family, service-delivery, community, national, and international levels*", (Schalock, 2005, p. 695).

Measurement of QOL is said to consider the degree to which people have life experiences which they value and one particular indicator of QOL is the extent to which people have interpersonal relationships (e.g. Brown, Branston & Hamre-Nietupski, 1979). Cummings and Lau (2003) suggest that close relationships are rated as being a highly important aspect of QOL, and where present often lead to the greatest satisfaction. Duvdevany and Arar (2004) also indicate that friendship activity is closely associated with the subjective quality of life for people who have LD. Literature suggests however that relationships are an aspect of life that is still experienced as being unsatisfactory by many people with LD (Bramston, Chipuer and Pretty, 2004; Forrester-Jones, Carpenter, Cambridge, Tate, Hallam, Knapp & Beecham, 2002; Fleming and Stenfert Kroese, 1990).

The literature on QOL however has been criticised on the grounds that the emphasis on operationalisation and measurement has led to an over-simplistic definition which reflects more of the values and needs of professionals rather than those of the people

that QOL initiatives are designed to support, (Rapley, 2003). In addition, much research undertaken to date has utilised quantitative measures such as the degree of satisfaction that people express regarding specific areas of their lives, and the number of opportunities that they have for particular experiences. With regard to interpersonal relationships it is argued here that it is not enough to simply look at the existence of relationships as an indicator of QOL, but to consider the meaning that those relationships hold for people with LD and the impact that this has for opportunities and subjectivity.

## **5 *History, Language, Meaning and Learning Disability***

Social Constructionism is a framework which posits that meaning is made in a social context – between individuals and through the interaction of social, cultural and historical factors. It also holds that multiple perspectives of a given phenomenon may co-exist at any time, and that meaning may change over time as it is renegotiated through social exchanges. An exploration of the history of ideas about learning disability points to the social construction of the category, which has been wrought with conflict and inconsistency.

### **5.1 The History of Learning Disability**

Prior to the nineteenth century, services to people classified as suffering from ‘idiocy’ (which was considered to be organic and permanent) mainly took the form of transient financial support which was provided for under poor laws. Many people who might have been classified as ‘idiots’ however were able to live in the community without any formal support. When assistance was provided it was given direct to the person classified as an ‘idiot’ in order to enable them to live independently, or directed towards family members or an identified carer who provided lodgings and care (Caine, Hatton and Emerson, 1994). At this time possessing ‘low intellect’ was usually of little consequence; this changed as society became increasingly concerned with economic growth, and skills and employability became requisite attributes.

The Industrial Revolution and the 'Enlightenment' influenced the privileging of reasoning ability as the definitive characteristic of being human. At this time people who had LD became increasingly visible in society as formal education was introduced and their ability to use reason was called into question. In this climate 'idiocy' was recast as a social problem and institutional care was considered an apt solution. The first institutions were run by voluntary agencies and their purpose was to train children identified as being 'idiots' to become productive members of society (Caine, Hatton and Emerson, 1994). Large state-run institutions soon followed, however. In contrast with the earlier voluntary institutions, the aim of these larger institutions was not eventual reintegration. Instead, there was a policy of permanent segregation and containment. This helped to reduce costs since much work could be undertaken by adult 'idiots'. Regimented routines also became a feature of these institutions as they ensured the smooth running of the organisation (Carlson, 2005).

In the early twentieth century, the power of the institution grew as 'idiocy' became reconceptualised as a threat to society (Caine; Hatton and Emerson, 1994). The eugenics movement considered idiocy to be a heritable condition and espoused that many of society's 'problems' (such as poverty, crime and immoral behaviour) were due to inferior genetic stock. The growth in popularity of cognitive testing played a contributory part in the development of these ideas. In the USA there were claims that cognitive testing demonstrated a link between low intelligence and criminality. People classified as being 'defective' (in the UK this term referred to people classed as 'idiots' 'imbeciles', 'feeble-minded persons' or 'moral defectives' according to the Mental Deficiency Act of 1913) were thus considered to be a menace and a burden to society. There were also claims that they were reproducing at a greater rate than 'ordinary' people (which was thought to occur particularly because men and women who were classified as 'defective' were thought to have highly sexual proclivities and low personal control). Consequently, opportunities for reproduction



were limited through isolation, sterilisation and restrictions on marriage (Race, 2002).

From the 1970's the power of institutions began to diminish. New evidence of the debilitating effects of institutional living, coupled with a series of scandals relating to abuse and neglect within long-stay hospitals led to a move to develop community services. The new philosophy of 'normalisation' (Wolfensberger, 1972) which later became 'Social Role Valorisation' (Wolfensberger, 1983) recast disability as the devaluing experiences which people with learning disabilities were subjected to in society. Enhancing social status was seen as the means to overcome disability, and these beliefs remain influential in current service provision (Baum, 2006). The current impetus is for people with learning disabilities to live 'ordinary' lives (Department of Health, 2001) and services aim to promote community inclusion, independence, choices and rights.

## **5.2 An Alternative Approach**

The idea that LD is an organic condition retains popularity; however Goodley (2001) presents a social model of LD which offers an alternative perspective. In defence of the turn to a social perspective, Goodley considers the diagnostic criteria that are used to define LD and argues that rather than originating in the individual, their historical, political and socio-cultural origins have been exposed. To further support a social model, he offers accounts of how particular stories of impairment and ability are told and given meaning in different contexts. Such stories offer alternatives to the problem saturated discourses often invoked by professionals, and can emphasise positive attributes such as resilience and capability. Furthermore it is proposed that emergent resilient cultures of people who have LD (such as self-advocacy groups) re-culturise impairment, and that attention should be paid to the ways in which assumptions about the origins of LD impact on how people who are given that label are treated.

### 5.3 Learning Disability and the Power of Language

A number of studies support the need for a model of LD which considers the role that social processes play in conveying particular meanings. Danforth and Navarro (1998), propose that the language and concepts of LD are a cultural option with which differences across the human population are managed. They conducted a study in which speech acts referring to LD which occurred within a non-professional context were sampled. Themes of: category membership; the dichotomy of 'normal' and 'abnormal'; issues of physical separation and psychological distance; and, fear were identified.

People who have LD and who are in receipt of services typically find that they become the subject of numerous written records which are collected and stored by the service. The language in these records also serves to reinforce particular ideas about them, and obscures others. Dimitry (2000) examined the case file of an individual labelled as having LD, with the aim of unravelling some of the mechanisms through which a defective identity was constructed, thereby legitimising social control. Dimitry noted how powerful professionals and institutions could define and control 'the norm' and those who were measured against it. He described how the subject of his case study was examined and subjected to a normalising judgement with regard to his intelligence, the effect of which was the construction of his identity as: "an imbecile" and later as a "mental retardate". Furthermore it was noted that these constructions legitimised: the act of placing him in an institution; his exclusion from school and other opportunities to learn; his exclusion from other activities; and, the disregard of alternative explanations which might have located his difficulties in situational rather than intrapersonal characteristics.

Danforth (2000) also applied Foucauldian thought to the field of developmental disabilities, pointing to the inextricable nature of power and knowledge and the risk of 'knowing' a person through their score on an intelligence test. He argued that through this process an individual was defined as lesser, defective and deficient, and



actions such as subjecting the person to detention and treatment were legitimised. Danforth further noted how power can be used to discipline and punish – at first overtly by the agencies of power, but covertly over time as the individuals subject to external controls repress and subjugate themselves through vigilant self-monitoring. External controls then fade from prominence as individuals become docile, obedient and compliant. This has clear parallels in learning disability services where behaviours defined as ‘unacceptable’ might initially be punished or prevented by staff responsible for managing the environment, and later eliminated through treatment programmes which teach the individual to regulate their own behaviour to conform to the norm.

The studies outlined above raise interesting theoretical issues but are removed from the lived experience of people with LD. One of the aims of the present study is to consider what people who have LD have to say about their relationships, what processes are suggested by their language, and what meaning can be derived from those accounts.

## **6      *Concluding Comments***

It is accepted that interpersonal relationships are significant to an individual’s experience and quality of life. Such relationships are constructed and maintained within a particular social context, and for people who have LD that social context is closely tied to the power and actions of services and carers. It is notable that little work has been undertaken to explore how particular types of relationships might be constructed within LD services. The current study will attempt to address the following questions:

- How do people who have LD, and those who work with them, talk about relationships – what constructions of relationships are revealed in that talk, and what meaning is implied in those constructions?
- What opportunities and/or restrictions for the positioning of individuals, for practice and for subjectivity are invoked by particular constructions?

- In what ways are particular constructions more powerful than others, how is this power maintained, and how might it be undermined?

## CHAPTER 2: METHOD

In this chapter I outline the theoretical rationale which guided my choices in methodology, I describe the setting in which the research was undertaken and the decisions and processes that I engaged with in order to ensure that this research was ethical, credible and coherent.

### *1 Theoretical Methodology*

#### **1.1 The Use of a Qualitative Approach**

The subject matter with which this research is concerned is the meanings of relationships as they are constructed and experienced by service-users and those working with them. It is felt that the context within which those relationships occur is crucial to the development of those meanings; therefore it is appropriate to use a qualitative methodology which privileges rich contextual data, and the nuances of individual experience. The research does not seek to investigate a causal relationship and it would be inappropriate to use a quantitative method that would impose pre-defined categories and meanings to the subject matter, and which may hold little relevance for the research participants.

#### **1.2 The Use of Discourse Analysis**

I analysed the data that was produced through this research within the theoretical framework of Foucauldian discourse analysis. This method of analysis is based on a philosophical viewpoint that considers discourse to be embedded within a socio-historical context that facilitates the production of certain discourses and limits the production of others. Dominant discourses make available certain ways of seeing the world and certain ways of being in the world, and are thus strongly implicated in the exercise of power (Willig, 2001). Discourse analysis attends not only to what is *said* in discourse but also to historical factors that have shaped discourse, and the

relationships between discourse and social institutions and practices. It does not aim to reconstruct the objective reality of an experience but to examine the conditions that make particular accounts possible, and the meanings that they hold (Parker, 1992).

Dominant discourses are considered to legitimise and perpetuate the social structures and social realities within which they are produced, thus the use of such an approach may be particularly pertinent to work in the field of learning disability. People who have learning disabilities are categorised as such on the basis of an assessment in which their abilities (cognitive and social) are questioned and judged against a pre-defined 'norm'. Danforth and Navarro (1998) argue that the diagnosis of learning disability relies on the words and actions of professional for its existence, whilst Dreyfus and Rainbow (1982) argue that the 'norm' is an arbitrary limit and one which is used as a principle of coercion. Once a person is positioned as being outside the norm or 'abnormal' particular discourses become available which help construct a defective identity (Dimitry, 2000). The construction of this identity legitimises particular practices, including the provision of specialist services, and continued supervision and recording which perpetuate the 'defective identity'. These practices are particularly apparent in learning disability services where extensive records about service-users' behaviours are made, stored and communicated to others. Foucault (1979) argued that observation is a political act and that each individual becomes a 'case to be known' through the recording of the minutiae of everyday life. Through such processes individuals are objectified and subjugated.

In using a discourse analytic approach I have adopted a critical realist position (Parker, 1992). This position holds that whilst discourse has the power to create versions of reality, and particular versions have real effects, discourse is not entirely independent of the material world. Reality informs the language we use to define the world, and our capacity to act in particular ways and construct particular versions is constrained by material and discursive resources (Gough & McFadden, 2001).



There exists another version of discourse analysis which is sometimes termed 'discursive psychology' (Willig, 2001). This version of analysis is also concerned with the role of language in constructing social reality, but attends more closely to the ways in which language is used to negotiate and manage social interactions to achieve interpersonal objectives, rather than the resources that are available to people when they use language. The availability of resources is closely linked to power. As people who have LD are often marginalised and disempowered I felt that it was important to attend to this difference and to consider the ways in which differences in power were maintained and how they might be undermined. Other qualitative methodologies were also discounted, for example Interpretative Phenomenological Analysis (IPA) would offer opportunities to explore how people understand relationships but would reject the possibility of understanding how language works to actually constitute that experience.

### 1.3 The Use of Interviews

I chose to use semi-structured interviews as the primary means of exploring the research topic, as discourse analysis holds that it is through language that meaning is made and knowledge constructed, therefore it was appropriate to utilise a language based method. Furthermore, the use of interviews enabled consideration of events and experiences that would have been impossible or ethically inappropriate to access by other means.

People with learning disabilities often experience difficulties in receptive and expressive communication, thus much qualitative research in the field of learning disability often relies on interviews with the staff or carers of people with learning disabilities, acting in the role of informant, in order to explore the subject matter. Duckett and Fryer (1998) commented that there was "*very little evidence that this population was offered a voice through, or had any control over, the research being conducted into their lives*" (pp.58). One of the aims of this study was to explore

relationships from the perspective of service-users. There are several published studies which demonstrate that people with learning disabilities can engage in research which aims to study their experience as it is constructed in their own words. Davies and Jenkins (1997) interviewed young adults with learning disabilities and explored how the categorical identity as being somebody who had a 'learning disability' was incorporated into their self-identity. Sequeira and Halstead (2001) employed semi-structured interviews with women who had learning disabilities to explore their experience of restraint. Scior (2003), interviewed women with learning disabilities to explore how they positioned themselves in relation to concepts of gender and disability, whilst Roets and Van Hove (2003), used interviews and naturalistic dialogue to compose a narrative analysis of the lived experiences of two women with learning disabilities.

There are limitations in the use of interviews (Potter and Hepburn, 2005). In the first instance there is the issue of interpretation, and whether what is presented is a reflection of what was *meant* by the speaker, or whether it represents how the researcher has *understood* what has been said. The current study offers an account of my understanding of the data I collected. Issues relating to the credibility of my interpretation are considered in the discussion. Furthermore, it is acknowledged that the involvement of the interviewer will have an impact on *what* is talked about and *how* it is talked about. In this research every effort was taken in order to make interviewees feel comfortable and at ease, however it is likely that interviewees did still censor and adapt what they said, in line with what they felt was socially acceptable or what they believed I expected. As an example one participant described her partner as "*too sexy*" but seemed embarrassed when I asked her if she could tell me more about what this meant to her – she changed the subject. It is also worthy of note that in choosing interviews as my primary data source, I excluded many service-users who had difficulties in expressive and/or receptive language from participating in this aspect of the research. It is however still appropriate to consider the impact that particular discourses may have on the lives of people with

learning disabilities who have limited verbal skills. The use of observations offers some useful additional data in this respect.

Particular consideration should be given to the issue of acquiescence when interviewing people who have LD. It has been suggested that people who have LD demonstrate acquiescence in interviews situations, and there is a sizeable body of literature which argues that people who have LD demonstrate a pre-disposition to give what they believe are desirable answers in interview; and in particular a tendency to give a “yes” response when faced with a yes-no question type (e.g. Sigelman, Budd, Spanhel and Schoenrock, 1981a; Sigelman, Budd, Spanhel and Schoenrock, 1981b). Furthermore Heal and Sigelman (1995) suggest that this effect is more pronounced when persons of ‘low status’ are questioned by ‘high status’ interviewers. Other literature (e.g. Flynn, 1986) has suggested that people who have LD may give inconsistent accounts of their experiences. The effect of such work has been to cast doubts on the validity of responses to questions given by people who have LD, and at times this has resulted in their exclusion from research and other activities which rely on the ability to self-report. Rapley and Antaki (1996) however suggest an alternative means of understanding the phenomenon. They argue that these studies in fact demonstrate a range of strategies which participants drew on when faced with bizarre or threatening questions. Finlay and Lyons (2001) reviewed the literature relating to difficulties in interviewing and using self-report questionnaires with people who have LD. They noted at least eighteen potential problems and offered suggestions for ways in which these difficulties might be overcome. The study points to the complexities in conducting interviews with this population, and provides a rationale for drawing on additional naturalistic methods to support the data.

#### **1.4 Number of Participants**

There is no published guidance with respect to how many participants are required for a study such as this one. Published papers which have used such a method have

varied widely with regard to the numbers of participants they have used. Scior, (2003) and Sequeira and Halstead, (2001) interviewed five participants; Hinsby and Baker, (2004) interviewed four nurses and four patients; Davies and Jenkins, (1997) interviewed sixty young people and fifty-seven parents or carers; and, Johnson, (1998) conducted one hundred and twenty interviews with staff, families of patients, and other professionals involved in the organisation in which her case study was situated. Given the research aims, and the methods being utilised it was felt that 12 interviews would generate sufficient data to explore the research topic and furthermore that this number would be practicable within the constraints of a doctoral thesis.

### 1.5 The Use of Observations

Although discourse analysis is most commonly applied to speech or writing, it is suggested that it is a method of analysis which can be applied “*wherever there is meaning*” (Parker, 1999, p.1), and that it can offer important insights into materials that are not normally thought of as being textual. Observations of social interaction and physical structures can offer insight into how discourse shapes what people do, and how what people do maintains and develops discourse.

The use of observations in this study enabled relationships to be explored from a different angle. Rather than only analysing what was said about relationships, it enabled an analysis of interactions as they were seen to occur, and of what may be ‘spoken’ by the physical and material structures that constitute an important part of the daily life of staff and service-users who attend the centre.

For the purposes of the study I chose to focus my observations around three different activities/structures:

- I observed the weekly service-user meeting. This was a formal activity which was chaired by staff, and involved a large proportion of the service-users who attended the centre.



- I observed interactions between individuals as service-users left the building at the end of the day. This enabled me to capture data that arose from less formal transactions between individuals.
- I observed the physical appearance of the exterior of the centre building. This enabled me to consider what might be communicated about the building and its business to people in the local community.

In addition some further observational data was collected incidentally simply as a result of my being present in the centre at particular times, and my interactions with staff and service-users. Though the collection of this data was unanticipated, it yielded pertinent additional insights at times.

### **1.6 The Use of an Organisational Case Study Approach**

The decision to focus this research around a single centre providing day services to service-users has important advantages and limitations. It was hoped that the research would provide a detailed and contextualised description of the accounts employed by *some* service-users and *some* staff and professionals who work with the centre. The utility of such an approach has been demonstrated by Brandon (2005) who highlights conflicts between the ‘posture’ of organisations – the formal values and beliefs that are espoused in policy; and the ‘culture’ of organisations – the unofficial day-to-day presentation of the service. He argues that interventions which are targeted only at the level of service policy will fail to have an impact unless they take into account the service culture. The use of a case study approach allows for a detailed exploration of service culture in considering the discourses that shape practice.

## **2 Ethical Issues**

Ethical Approval for this study was granted by Harrogate Local Research Ethics Committee (See appendix 1).

## 2.1 Consent

Interview participants had to be able to give informed consent. Participants were asked to consent to take part in the study, and to the recording, transcribing and quotation of interview material. The process of ensuring that consent was valid was informed by the Department of Health publication: 'Seeking consent: working with people with learning disabilities' (2001) and The Mental Capacity Act (2005).

Information was given in an accessible format to support potential participants to make their decision. Written material (a project poster and service-user information sheet) were supplemented with symbols where appropriate in order to facilitate comprehension. This was done in consultation with the Inclusive Symbolic Language Service, which has worked with service-users to develop a range of symbols to help make information for people with LD easier to understand. Information about the project was provided in the following ways:

- I discussed the project with service-users at their weekly meeting.
- I discussed the project with staff-members at their monthly staff meeting.
- I displayed posters around the centre which gave some general information about the project (see appendix 2).
- Potential interview participants were given information sheets (see appendix 3) when they met with me to discuss the project and the possibility of their being interviewed. I also reiterated the information contained in these sheets verbally at this time.

Once an individual had been identified as a potential interview candidate, I met with them to discuss the project in more detail, to guide them through the information sheet, and to gauge their ability to give informed consent. In doing this I tried to ensure that participants were able to: comprehend and retain the relevant information; use and weigh this information in the decision-making process; and, communicate their decision. I did this by asking a mixture of closed and open questions, for example:

- *“Can you tell me about some of the things that are written on this piece of paper?”*
- *“What do you think will happen if you decide that you don’t want to take part?”*
- *“Do you want to take part?”*

Participants were also given the opportunity to ask me any questions that they might have. I used a consent checklist to guide me through the consenting process (see appendix 4). If the person indicated that they wanted to take part and I felt that they had been able to give informed consent, we negotiated a time when I would come back to interview them. When meeting with participants for interview I asked them if they could recall what we had spoken about last time and whether they were still happy to take part. No participants indicated that they did not wish to take part however a number of participants did not refer to key aspects of the research project when recalling our prior conversation. In these instances we briefly discussed these features before proceeding.

Informed consent should be embedded throughout the research process rather than a one-off event (Department of Health, 2001). As one interview with a service-user unfolded I began to doubt that his consent was valid. His responses to my questions suggested to me that I had not been understood (he tended to repeat back my question and then add “yes”, even when a yes/no response did not seem appropriate). I tried a number of different presentation styles in an attempt to make myself understood but none resulted in a congruent response, therefore I eventually decided to abandon the interview as an ethical principle.

Another feature of informed consent is that it should be freely given (Department of Health, 2001). One service-user I met appeared to be very anxious about my meeting with him, and worried about the prospect of my coming back to talk to him about his relationships. From this person’s interaction with me I felt sure that he did not want to take part, though he did not explicitly state this. I decided therefore not

to interview him as I believed that he may have felt under obligation to take part despite my assurances to the contrary.

## **2.2 Confidentiality**

The interview recordings were transcribed. Seven interviews were transcribed by an external party, and in these instances the person undertaking the transcribing was asked to sign an agreement of confidentiality (see appendix 5). In order to preserve the anonymity of participants, I assigned each interview transcript a unique code consisting of letters and a number (e.g. SU1, SM4). The letters SU and SM indicate whether a person is a service-user or staff-member respectively.

I have tried to ensure that quotations from interviews that are presented in this report do not contain information that would make the individual identifiable (for example I have changed or deleted names, locations and personal information); however owing to the small number of participants it is likely that participants will recognise their own contributions. In addition it is worthy to note that the way in which the centre operates (and thus the way in which I acted whilst within the centre), and the use of a case-study approach pose particular challenges to confidentiality. For each interview I undertook I negotiated a time and date with that person, however this was then recorded in a diary at the centre to ensure both that a room was made available for our interview, and that that person was not required to engage in any other activities at that time and/or that their duties could be covered by other members of staff. The result of this however is that staff at the centre knew who took part in interviews. It is also clear from my involvement with staff at the centre, that they often have access to intimate details of service-users' lives. Therefore there remains a risk that quotations used in this account might enable staff to identify the individual(s) who gave them. I have tried to guard against this to the best of my abilities.



### 2.3 Potential for Harm

I did not seek to ask participants to describe difficult or negative experiences in this research; however in the planning stages it was acknowledged that the process of being interviewed about relationships had the potential to precipitate some psychological distress for participants. Prior to undertaking interviews and following discussions with supervisors, I devised a procedure, which would be implemented in the event that an individual became distressed. In one interview a participant became upset whilst talking about a bereavement. At this time the person in question was offered support and reminded that they could withdraw from the study if they wished (stage 1 of the procedure). In this case the person decided to continue and was given time to compose themselves. In the debriefing the person was offered the opportunity to talk about the impact that the interview had had on them (stage 2 of the procedure). At this point the person told me that although they had felt upset they had liked thinking about and talking about the person who had died. They stated that they did not want any additional support; therefore it was not appropriate to implement any of the further stages of the procedure.

### 3 *The Service*

The service in which this research was based was a large centre which provided day services to people who have learning disabilities who live locally. On a typical day the centre will provide services to approximately sixty service-users, and over the course of a week approximately eighty five service-users will access the centre. Service-users participate in a range of activities at the centre including arts, crafts, and domestic skills. A number of service-users are also supported to attend activities outside of the centre, such as college courses, gardening work and leisure pursuits such as swimming. Service-users are assigned to groups, and each group has an identified 'keyworker' who is a member of staff whose role it is to ensure that service-users who are in their group access activities that meet their 'needs'. Assignment to a keyworker is based on a number of characteristics including 'ability' (one group of service-users are said to have high support needs).

#### 4 *Recruitment*

Recruitment for interviews was done on a case by case basis. At the outset I liaised with a senior member of staff at the centre to identify one staff-member and one service-user who they felt would meet the inclusion criteria. The inclusion criteria were: that the person might be interested in participating, was thought to be able to consent and could articulate their emotional experience. In addition people who had an autistic spectrum disorder were excluded, as it was felt that people with such a diagnosis might manage and make sense of their relationships using different frameworks to others who did not have such a diagnosis. It was felt that it might have been difficult to give justice to these other frameworks within the scope of this research project. The inclusion criteria were relevant to both staff and service-user groups.

In the case of service-user recruitment, once a potential participant had been identified, the senior staff member approached the person to ask if they were interested in meeting me and finding out some more about the project. Reports from staff indicated that three service-users who were approached about the project opted not to meet with me. If the person did agree to meet with me, I then met with that person to discuss the project and address issues of informed consent. If I felt that the person was able to give consent I arranged a time to interview them. In the case of staff-member recruitment, a senior member of staff approached the person to ask if they might be interested in participating in the project. If that person indicated that they were interested I contacted them by phone to discuss the project in more detail and to arrange a time for interview.

Inclusion criteria for the initial interviews were very broad; however as interviewing progressed I attempted to include participants with specific demographic attributes or experiences and actively selected for these characteristics. Gerson (2002) suggests that these varieties of social location “*pose different dilemmas, offer unequal resources and create divergent options*” (pp.205). Although in the planning stages of the research a number of characteristics were identified that might

have been important in structuring individual accounts, in practice it was not always possible to identify potential participants who possessed some particular characteristics. For example characteristics that might have been important to service-user accounts included: age, gender, sexuality, ethnicity, experience of living in institutions and so on. In practice the service-users who participated were selected for difference in age, gender, length of time spent at the centre, experience of institutional living and experience of long-term intimate relationships. A number of participants also had physical disabilities though this was not actively selected for. Similarly, characteristics that might have been important to staff accounts included: age, gender, sexuality, ethnicity, seniority, and length of service. In practice staff participants were selected on characteristics of age, gender, seniority and length of service.

In accord with the view that qualitative research can be an iterative process, it was assumed at the outset that interviews with service-users might highlight themes that I would wish to explore further in staff-member interviews and that similarly, interviews with staff-members might draw my attention to issues that I would wish to develop in interviews with service-users. With this in mind I decided to begin data collection with three consecutive interviews with service-users, followed by three consecutive interviews with staff. I then completed a further three service-user interviews and concluded the interviewing process with interviews with three more staff-members.

#### **4.1 Service-User Participants**

Six service-users were interviewed as part of this research project. Of these six service-users two were male, and four were female. They were all adults and their ages ranged from mid-twenties to mid sixties. The length of time that participants had spent in the centre ranged from less than one year to more than twenty years. Two of the participants lived at home with their parents, two lived in small (less than 5 residents) staffed homes and two lived in large staffed housing.

## 4.2 Staff Member Participants

Six staff-members were interviewed as part of this research project. Of these three were female and three were male. Their ages ranged from early thirties to late fifties. The length of time that participants had worked in the centre varied from one year to more than twenty years. Four staff-members held relatively senior posts in the centre; one held a junior position and one person worked for part of the week in a junior position and the other half of the week in a senior position.

## 5 *Interviewing*

In interviewing participants I used open-ended questions intended to facilitate participants in telling their own stories rather than following a fixed question-answer format. I used a topic guide to help me structure the interviews and ensure that I covered all of the areas I wished to explore (see appendix 6). An outline of a service-user interview is given in Table 1, and an outline of a staff-member interview in Table 2. For service-user interviews my initial questions were designed to ascertain something of the network of relationships that participants had, and participants were invited to select a person to talk about in more depth. The process was repeated for others in the network as time allowed. For staff interviews, I asked participants to talk about their own relationship with a service-user (whom the participant chose). Following this I asked the staff-member if they could tell me about a service-user they felt they knew well, and asked questions about their perceptions of that person's relationships.



**Table 1: Service-User Interview Outline**

<b>Service-User Interviews</b>	
<b>1.</b>	<b>Orientation</b> - Reintroducing self and the purpose of the interview, checking that the person is still willing to proceed and that consent is valid.
<b>2.</b>	<b>Context</b> - Finding out some information about the person – where they live, how long have they been there, who else lives there, etc. Also how long have they been coming to the centre, what sort of things do they do there, etc.
<b>3.</b>	<b>Relationships that the person has/had</b> - What relationships do they have/have they had, how did they get to know that person, what sorts of things do they/did they do in their relationships.
<b>4.</b>	<b>What are/were those relationships like?</b> - What feelings does the person have when they're with that person, what is their understanding of <i>why</i> things are a particular way.
<b>5.</b>	<b>Expectations</b> - Checking out how they think things will develop, if relevant.
<b>6.</b>	<b>Social Context</b> - Exploring social influences on the relationship, what others say and do, etc.
<b>7.</b>	<b>Different Ways</b> - If there are things that the person would like to be different about their relationships what stops it from being the way they would like it to be?
<b>8.</b>	<b>Debrief</b> - Checking out how the person has found the interview and how they feel now.
<b>9.</b>	<b>What happens next</b> - Explaining how the research will proceed, reiterating what happens with their information.
<b>10.</b>	<b>Thanks</b>

**Table 2: Staff-Member Interview Outline**

<b>Staff-Member Interviews</b>	
<b>1.</b>	<b>Orientation</b> - Reintroducing self and the purpose of the interview, checking that the person is still willing to proceed and that consent is valid.
<b>2.</b>	<b>Context</b> - Finding out about the person – how long have they worked in their current post and what sorts of things does their job entail. Work biography.
<b>3.</b>	<p><b>Their own relationship with a service-user</b> – How did the relationship develop, what sorts of things do they do?</p> <p><b>What’s that relationships like?</b> – How do they feel when they’re with that service-user, what is their understanding of <i>why</i> things are a particular way.</p> <p><b>Expectations</b> - Checking out how they think their relationship with that service-user will develop.</p> <p><b>Social Context</b> - Exploring social influences on the relationship with a service-user, what others say and do, etc</p> <p><b>Different Ways</b> - If there are things that the staff-member would like to be different about their relationship with a service-user, what stops it from being the way they would like it to be?</p>
<b>4.</b>	<p><b>Their perceptions of a particular service-user’s relationships</b> - What sorts of relationships does that person have? What sorts of things do they do in their relationships, etc.</p> <p><b>What do they think the relationship is like?</b> - How do they think the service-user feels when they’re with particular people, what meaning do they think the service-user draws from their relationships?</p> <p><b>Expectations</b> - How do they think the relationship will develop?</p> <p><b>Social Context</b> - Exploring social influences on the relationship, what others say and do, etc.</p> <p><b>Different Ways</b> – Do they think that the service-user would like the relationship to be different, and if so what stops it from being the way they would like it to be?</p>
<b>5.</b>	<b>Debrief</b> - Checking out how the person has found the interview and how they feel now.
<b>6.</b>	<b>What happens next</b> - Explaining how the research will proceed, reiterating what happens with their information.
<b>7.</b>	<b>Thanks</b>

The interviews were recorded and transcribed either by myself or an independent transcriber. To facilitate the reading of transcript I adopted a number of conventions (See Table 3).

**Table 3: Transcription Conventions**

.	Short pause
...	Longer pause
[laugh]	Information on non-linguistic features
[?]	A small segment of text which was inaudible
[????]	A longer segment of text which was inaudible
[?text]	A segment of text which may be inaccurate
-	An overlap in conversational turns

## **6 Method of Analysis**

Interview and observational data was analysed using discourse analysis.

### **6.1 Stages of Analysis - Interview**

At the outset I read and re-read the interview transcripts in order to become familiar with the accounts. I noted any initial responses and observations, before beginning formal analysis. The first six stages of analysis (1-6) were guided by Willig's (2001) procedural guidelines for the analysis of discourse. The final stage of analysis was designed to tap into the role of institutions, power, and ideology and was guided by the additional criteria described by Parker (1992). Table 1 outlines the stages of analysis. Although I have tried to neatly package my analysis of the texts into discrete stages here, it is important to note that in practice the boundaries between stages were sometimes ambiguous and the stages were not necessarily employed sequentially. An extract from an interview and a worked example of the analysis is given in appendix 7.

**Table 4: Stages of Analysis – Linguistic Data**

<b>Stage</b>	<b>Description</b>
<b>1. Discursive Constructions</b>	This stage involved identifying the different ways in which relationships were talked about and therefore constructed in the text. Implicit and explicit references were included.
<b>2. Discourses</b>	This stage of the analysis involved locating different constructions of relationships within wider discourses. Discourses have been defined as “ <i>a system of statements which constructs an object</i> ” (Parker, 1992: 5), they may also be thought of as particular ways in which meaning is imposed on social realities.
<b>3. Action Orientation</b>	In this stage of analysis, consideration was given to what might be gained by utilising a particular construction of a relationship at a particular time.
<b>4. Positioning</b>	Stage 4 of the analysis involved exploring how individuals (the speaker and others that they referred to) were positioned within the discourse, and the rights and responsibilities that these subject positions might afford.
<b>5. Practice</b>	In this stage of the analysis thought was given to the different opportunities for action that were made possible or impossible, by different discourses.
<b>6. Subjectivity</b>	This stage of analysis involved considering the range of subjective experience that might be made more or less possible for the individuals referred to in the text, from their various subject positions.
<b>7. Institutional Relevance, Power and Ideological Effects</b>	Consideration was given at this stage to: which institutions may be reinforced and/or which institutions may be subverted when a particular discourse is used; which categories of people might gain and lose from the employment of particular discourses; reflection on how a particular discourse may connect with other discourses; and, how particular discourses may allow dominant groups to tell their own stories about the past, preventing marginalised groups from making history.



## 6.2 Stages of Analysis – Observations

Relatively little has been written with regard to *how* to analyse visual texts, therefore the analysis of observational data was informed by Pearce (1997) and Bannister (1994). Pearce offers a framework that can be applied to visual images; the stages of this analysis are described in Table 5. An extract of observational data and a worked example of this form of analysis is given in Appendix 8. Although this framework helped me to understand the visual data that I described, in practice much of the data that was collected through observation was communicated directly in language (for example verbal exchanges between participants and written material that was displayed in and around the centre), where this was the case it was often possible to analyse the data using the principles described in Table 4.

**Table 5: Stages of Analysis – Visual Data**

<b>Stage</b>	<b>Description</b>
<b>1. Description</b>	In this stage of analysis the observational context, participants and observational focus were described. The actions of participants were described and/or physical features of the environment were described.
<b>2. Exploration of Connotation</b>	In this stage I considered what features of the observation appeared meaningful, i.e. what constructions they implied.
<b>3. Identification of discourses</b>	This stage of analysis was analogous to stage 2 described in Table 1
<b>4. Definition of subjectification</b>	In this stage of analysis I considered what subject positions for particular individuals were implied (analogous to stage 4 in Table 1), and the effects of this positioning (Analogous to stages 5 and 6 in Table 1).
<b>5. Search for similar discourses in other texts</b>	In this stage I noted other texts that invoked similar discourses, including my transcripts of interviews.
<b>6. Appreciation of historical dimension</b>	This stage involved consideration of the history of service-provision for people who have LD, and how my observations could be positioned within this history.
<b>7. Summary of overall structures of meaning</b>	In the final stage of analysis I tried to summarise how the data was made meaningful.

## **7 Research Diary**

I kept a diary throughout the research process which I used to reflect on how my experiences might influence the research. The following extract offers an insight into how it was used:

*“I attended ‘Vulnerable Adults Training’ as part of work today. Another person attending spoke about ‘Father Christmas’ going to a centre for people with LD. I*

*was waiting for him to comment that this action cast people with LD in the role of children and that this was demeaning, inappropriate and as such might be classified as a form of abuse. I was really surprised and angry when he did not make this point.”*

Reflecting on this entry helped me to see that at this stage in the research I was feeling very much attuned to particular aspects of the research such as issues of positioning and power. I was losing sight however of some of the other important issues, such as the historical origins of particular discourses and their relation to institutions – the explanation of how things came to be as well as the description of how they seem to be. This realisation prompted me to return to some of the literature surrounding the wider context within which discourses are situated.

The diary also enabled me to consider how the research led to my interpreting new experiences in particular ways. For example at a relatively late point in the research process I made the following entry:

*“Today at the centre Michael asked me where I lived. I told him that I lived ‘near [local town]’. I did not say [name of particular area]’. On my way home I thought about why this was. It was not just my usual reticence to divulge personal information to clients that I work with; there was more to it than that. I had noted that Michael was ‘of a certain age’ and thought that he had probably lived in institutions and most likely [name of local institution which is now closed]. I chose not to tell him where I lived because I did not want to remind him about that place – I wondered if doing so might upset him and I did not want him to associate me with that place. Later I realised that in doing so I had acted as though I needed to protect him. I started to wonder what might have happened if I had told Michael where I lived – we might have had a different sort of conversation. I might have discovered that he had never lived in [name of institution], or if he did I might have found out things about that experience. There might have been difficult memories associated with the institution but he might have felt it was valuable to talk about*

*those memories. I might have found out new and surprising things about that experience – perhaps he missed people who he used to see there, perhaps there were things about the hospital that he liked?”*

This entry made me more feel more sympathetic towards staff. It reminded me that it is very easy to act within particular discourses – it can be instinctive and difficult to resist. I also felt somewhat embarrassed about the way in which I had acted and this gave me some ideas about what it might be like for staff to hear about how their accounts had been interpreted. I felt that it was important to acknowledge my own fallibility in any account of the research. After discussing the incident in supervision I also felt a degree of hopefulness about what had happened – although dominant discourses are often ‘taken-for-granted’, the process of critical reflection had made me more aware of what ideas motivated my actions at this time and the subsequent consequences of my action. I also felt confident that should a similar situation arise, I would respond differently. This led me to speculate that some structure that enabled staff to critically reflect on the ways in which they related to service-users (and their practice more generally), might enable different ways of working to be identified, which may be more empowering for service-users.

## **8      *Quality of the Research***

There are a number of published guidelines which relate to the evaluation of qualitative research (e.g. Parker, 2004; Elliott, Fischer and Rennie, 1999), some of which complement the research methodology and some of which do not. Particular principles which I adopted and which were apt for the current study were:

- Exploring the subject matter from different vantage points – multiple methods were used in the current study. Within the context of this study triangulation was not conceived of as a means of establishing the reliability of a single ‘real’ phenomenon, since each account was taken as being a socially constructed entity; however the use of multiple perspectives added depth to my analyses.



- Owning my perspective – I have tried to ensure that the reader of this account knows something of my interest in, and experience of working within learning disability services in order to consider how my position might have impacted on the research. I have also tried to be transparent about my experience of undertaking the research, and the ways in which this influenced my work.
- Checking the credibility of my analyses – I attempted to establish the credibility of my analysis through utilising supervision as a means of critically reflecting upon the analysis and discussing the research with other psychologists working within learning disability services as a means of gaining multiple perspectives and new impressions. In keeping with the theoretical orientation of the research, the aim of these discussions was not to confirm or disconfirm my conclusions but to introduce the possibility of alternative understandings.
- Situating the account – I have tried to make the research process transparent by describing the setting, decisions, procedures and processes in detail so that recipients of this research report can make an informed decision about how valuable they feel the conclusions of this report to be, and how relevant the conclusions might be for other settings.
- Application – I consider what implications for practice the research has, and suggest what further research might add to the account presented here.

## 9 *Writing Up*

In my presentation of this study, I have reviewed literature that is pertinent to the research area. The strategies I used to identify this literature are contained in appendix 9. In the analysis section I utilise quotes from interviews, observational notes and my reflective diary to support my arguments. Quotes are presented in italics, with the source indicated. Square brackets indicate that I have omitted data that was repetitious, revealing or superfluous. In my commentary I have at times opted to use the plural pronoun ‘they’ rather than ‘he’ or ‘she’ in order to conceal gender and to protect the identity of participants.

## CHAPTER 3: ANALYSIS

In this section I shall apply the framework of discourse analysis to the data collected, in order to explore systematically the different ways in which relationships were talked about (and seen to be embodied in observable transactions and/or physical structures). This analysis draws primarily on the data collected from interviews with staff and service-users; however I have supplemented this with my observations and my personal reflections of the process, as I felt them to be relevant.

I present my findings under headings which relate to each of the stages of discourse analysis which have been described earlier. In the first instance I consider the different *discursive constructions* that I identified in the data – the different ways in which relationships were talked about revealing different ways in which relationships could be constructed and understood. This section acts as a foundation for the further analyses I present. I then discuss the wider *discourses* that these constructions drew on and which gave them meaning. Following this I move on to consider the discursive context in which particular constructions were utilised – the function of utilising particular constructions at particular times, or the *action orientation* of the dialogue. In the following section I turn my attention to *positioning*, that is the different subject positions that were offered by particular constructions. I then consider what opportunities for *practice* were legitimised or limited by the different positions which participants spoke from or were placed, before speculating as to what differences in *subjectivity* might be anticipated for individuals in their respective positions. In the final stage of the analysis I discuss the historical context of these findings, paying particular attention to how particular constructions and discourses are linked to issues of *institution, power and ideological effects*.

## *1 Discursive Constructions*

In this section I outline different ways in which participants constructed relationships. I look at relationships as: *'Emotional Attachment'*, *'Doing for'*, *'Guidance'*, *'Protection'*, *'Belonging'*, *'Authority'*, *'Aggression'*, *'Shared Experience'*, *'Empathy'*, *'Routine'*, and *'Physical Attraction'*.

### **1.1 Emotional Attachment**

One construction which participants drew on in their interviews was of a mutual relationship which involved affection and emotion. In one interview a service-user described her feeling towards her boyfriend: *"I love him so much"* (SU2, 33), she also described how she felt when he went away on holiday with his family: *"I know I'm missing him there... Cause I had a phone call off him... I know I'm missing him"* (SU2, 190 – 191). Another service-user also spoke about loving her boyfriend: *"I still love him, and he still loves me"* (SU4, 213). The depth of her emotional attachment was evident when she spoke with obvious sadness and frustration about the fact that she could no longer see him: *"I do not know where he's gone to... I don't know where"* (SU4, 282).

Emotional attachment towards parents was also evident: One service-user said of his mum: *"I love her unstoppable actually. I always tell her that I love her to bits"* (SU3, 494-495). Another service-user described her feelings about the possibility of her mum moving house:

Researcher: *"What do you think would happen if she moved to a different home?"*

SU5: *"I don't know, maybe I would get upset."*

Researcher: *"You might feel upset. Can you tell me why you might feel upset?"*

SU5: *"I do love her... but she might move... but she can't move she's got me at home".* (SU5, 283-286).

Feeling that one was loved in return was also clearly important. One service-user spoke of his relationship with his brother, and expressed sadness about the fact that he had not heard his brother say that he loved him: *“I don’t get a chance to see him. And he never gets the chance to say he loves me... Last time when I was very very ill, he said he loves me. And I don’t remember that”*. (SU3, 193-195).

Some staff-members also spoke of feeling emotionally attached to service users: *“You do form attachments to people and they also form a relationship with you. It’s reciprocated... I get on really well with him”*. (SM3, 172-174). In this construction the commonality between staff and service-users was emphasised; however other constructions of relationships could emphasise difference.

## 1.2 ‘Doing for’

Relationships were sometimes constructed as one person doing something for another *“That’s the good thing about being a key worker, because these people that you’re responsible for, you can do more for them”* (SM2, 225 – 227). Within the data collected by staff interviews, the person ‘doing for’ was almost always a staff member (or another person who did not have a learning disability), whilst the person having something ‘done for them’ was always a service-user.

Staff referred to ways in which service-users were dependent on others, and how particular ‘needs’ were met through their relationships. In the following extract I asked a staff-member why she felt that she was suited to working with a particular group of service-users: *“I think it’s because they need you more”*. (SM1 28-29). In addition staff also spoke about service-users turning to them for support. In the following extract a staff-member had described a service-user as being *“more of a staff person”* (SM1, 485). She gave the following explanation for why she thought this was so:



SM1: *“He knows he can come to you if he’s not feeling right [ ] he knows he can come to you if he has any problems. So I think he thinks of us as being there if he needs us really and he knows we’re there if he’s not feeling right”*. (499-502).

In one interview a staff-member discussed a service user’s relationship with his family:

Researcher: *“Right, so what sorts of things do they do?”*

SM3: *“Well they go to the caravan together, they go there... [ ] Also all his needs are met. They provide for him, all his meals are cooked, his washing’s done, his room’s tidy, the house is nicely decorated and he’s got all the comforts that he could wish for”*. (422-425)

In another interview I asked a staff-member how a particular service-user’s relationship with his parents compared to how other people might relate to their parents: *“It’s different because he’s dependent on them”*, (SM6, 429). This dependency was constructed as being expected and even desired by the service-user: *“He still looks to his parents to look after him to some extent”*, (SM6, 437).

Ideas about ‘doing for’ were also reflected in talk about service-users being ‘taken’ places by others, rather than (for example) ‘going with’:

Researcher: *“So what sort of things did they do together?”*

SM2: *“She used to take him out, she used to take him bowling or shopping”*. (SM2, 700 – 702).

Researcher: *“OK. And your job now – what sorts of things are you doing now?”*

SM4: *“I stay in like maybe half the week and take them out the other half, I enjoy taking them out, going swimming, bowling”*. (SM4, 25 – 28).

Service-users also described how they were 'taken' places by others: "*Mick sometimes takes me to the pictures.*" (SU3, 393).

The construction of relationships as involving service-users being dependent on others to meet some need marks out service-users as lacking some resource that others have; however some service-users spoke about the ways in which they themselves supported others. One service-user spoke about his relationship with another service-user who he had lived with for a number of years, in a large residential hostel. He described the various ways in which he currently cared for this person, and how he would sustain this when they moved to separate residences: "*He's going to live in one of the new houses. I'll catch a bus down there, see to him, then catch a bus back*", (SU1, 302-304). This same participant described how he was helped by another service-user when he broke his arm: "*That's when Denise started cutting up food for me. She started feeding me*" (SU1, 145).

Other service-user participants also spoke of doing things for one another in their relationships; however this tended to have the flavour of a more reciprocal relationship. For example one service-user described her relationship with her partner in the following way: "*He always helped me a lot, because I always help him. Take it in turns*". (SU2, 33-34). Acts of doing that reflected kindness and generosity rather than need also characterised service-users' descriptions of relationships: "*He always made me a coffee, every night, and I always made him a coffee every morning*" (SU4, 321).

### 1.3 Shared Experience

Relationships were also constructed as doing things together. In these instances relationships involved shared experience and mutual interests:

*Researcher:* "What sorts of things do you and your Mum do together?"

*SU5:* "Together? We go out together."

Researcher: *“What sorts of places might you go together?”*

SU5: *“The pub. We might go drinking. I can drink. You haven’t seen me drink have you?”* (SU5, 161-165).

One service-user showed me numerous photos of her and her boyfriend dancing together, and told me *“We love it, dancing”* (SU4, 234). Another staff-member commenting about a service-user’s relationship said: *“Stefan’s really good at ballroom dancing...and Lisa’s really good at mimicking dances...and she’ll twirl round...really enjoys it, and Stefan’s there holding her hand”*, (SM3, 569-575).

In intimate relationships, relationships with others might also be shared: *“See like Katy? She’s our friend”*. (SU2, 238).

There were also times when staff drew on this construction to describe their own relationship with service-users:

SM5: *“He’s a very similar age to me, just two years younger... We’ve got a great deal in common because we can remember so much. He’s into trams, trains, buses and things. I was a bit of an anorak, a bit of a train spotter in my younger years, but it’s nice that you can actually talk to somebody, they actually know things about the war because everything was so much based on the second world war... Even your comics and everything, the stories carried. And he remembers quite a bit of these things, you can actually talk with a little bit of knowledge as opposed to ‘Oh yes, is that what happened?’ And you can put your own bits in and he really likes that”*

Researcher: *You’ve got a shared understanding rather than just someone telling you?*

SM5: *It becomes more of a friendly thing if you like. We could have sat down and had a pint between us and sort of sat down and had some of the conversations rather than it being at a workplace”,* (398-414).

In this case the interaction described by the staff-member would be very ordinary in another setting; however it seemed extraordinary in the context of this research. The sense of equality and lack of difference that was conveyed in this extract was in sharp contrast with other constructions which emphasised disparity.

#### **1.4 Guidance**

One of the most prevalent themes in staff-members' transcripts was that of guidance, and in particular the construction of service-user's relationships as involving the provision of guidance. Guidance was exclusively 'provided' by a person who did not have learning disabilities. For example some staff used their relationship as a means to educate service-users about moral behaviour:

SM5: *"Some probably didn't really understand – or maybe were not taught the difference between right and wrong, whereas you do now. You try to teach them a little bit more what is right". (182-184).*

Guidance also took the form of teaching culturally expected behaviours:

SM5: *"There is a lot of teaching in small ways, even if you're taking people toileting you're just having to remind them to wash your hands cause it's so easy to forget things like that... Even in the dining room we sometimes have to remind people that. I always think that if you're going to take people out in the community, if you've got decent manners it's far easier to integrate". (186-191).*

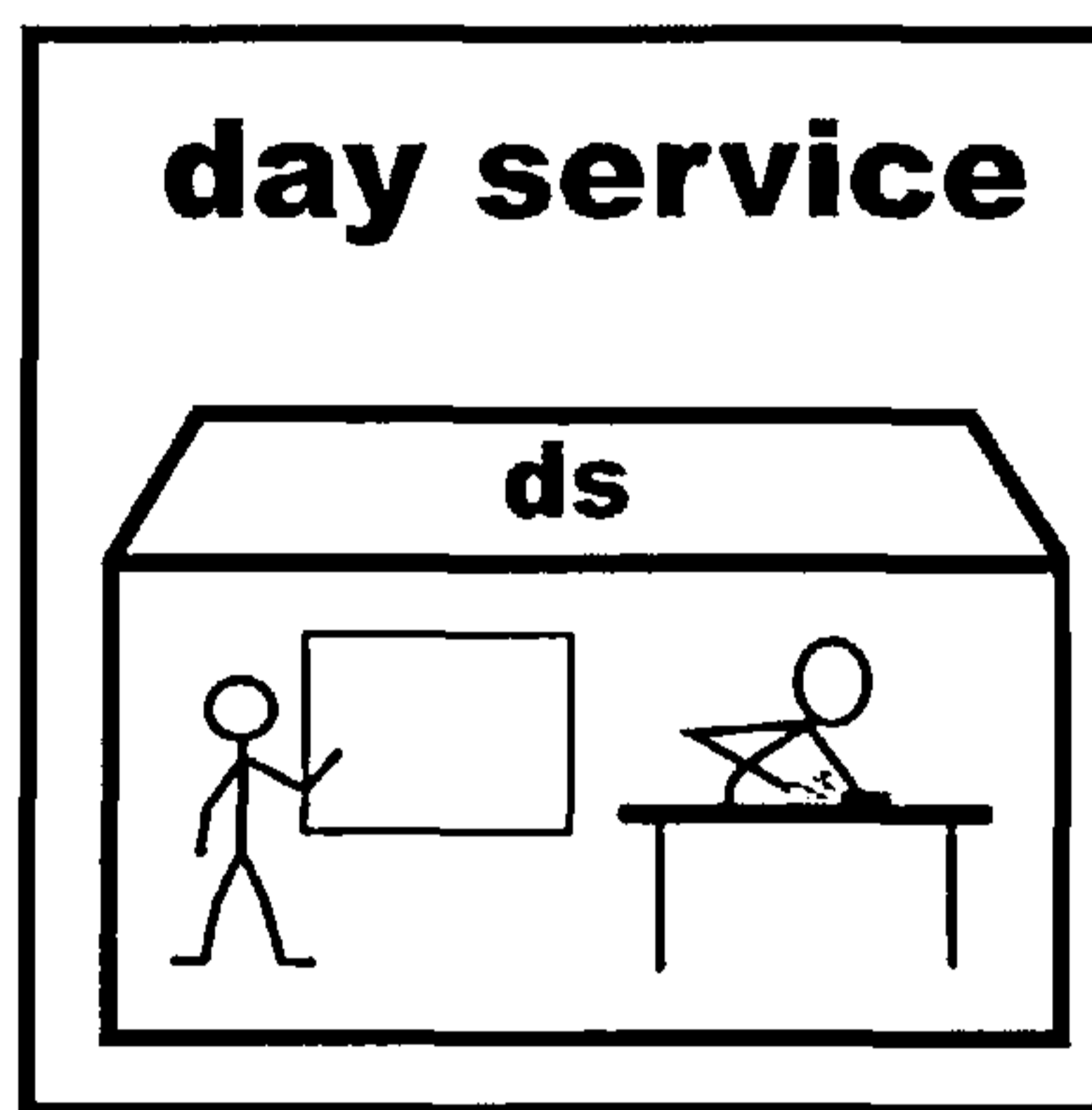
Staff also discussed how they tried to build up service-users' skills in particular areas:



SM3: *“I do a communication session here, I have two groups, one group is more advanced than the other. We’re going through various topics showing them signs and we’re working on their receptive skills and their productive skills”*. (95- 98).

This construction of relationships as involving ‘being taught’ and ‘developing skills’ might also be seen to be embodied in the day service sign which I observed at the front of the building. The dominant feature of the sign was a symbol which is reproduced in figure 1.

**Figure 1: The Day Service Symbol**



The symbol demonstrates two activities that one might expect to take place in the centre. One part of the sign shows a stick figure pointing to a board – this is reminiscent of a teacher addressing a class, and in interpreting this it is assumed that the stick figure represents a staff-member as opposed to a service user. The ‘identity’ of the other figure is more ambiguous – this figure looks to be working with some sort of tool. The symbol may be designed to capture two separate activities that take place in the centre or that the figure at the board is teaching the other figure about ‘work’. This symbol was also reproduced in the information sheets that were developed for this research project – thus it can be argued that this project utilised and reinforced the construction of relationships between staff and service-users as involving the provision of guidance.

The construction of relationships as involving the provision of guidance highlights developmental concerns. Service-users are again noted to be lacking in some way, however in this construction there is emphasis on developing competence. Staff's role in this construction then is to foster service-users' growth through the provision of guidance.

## 1.5 Protection

It was apparent that staff members also constructed their relationship with service-users as involving a duty of protection - to ensure that service-users did not come to harm, and to avoid any distress. The source of this harm and/or distress may be another person (another service-user or a 'member of the public') or may be the service-user themselves.

Staff spoke about the potential for service-users to face abuse when in the community:

SM5: *"Because you see how vulnerable people can be, we probably tend to be a bit over cautious... Again it's coming back to the caring and you don't want them to face any forms of abuse. We don't really get much but sometimes you have young children who live in the area and they come round and we walk a group over the road and they'll be dashing around on their bikes and they think it's great fun to come quite close to them. The poor person that's on a frame, they're stopping and they feel quite unbalanced". (353-358).*

In contrast to the community which could be perceived as being 'dangerous' – the day service itself was referred to as a place of safety. In response to a question about the aims of the service one staff member replied: *"I think it's at a lot of levels...a lot of carers want their son or daughter to be away from home for a day somewhere safe". (SM6, 181-183).*

One service-user also spoke of the “dangers” that people might fall prey to “on the street”:

Researcher: *“One of the things you’ve told me is that in the future you hope you’ll have a girlfriend and friends. I’m wondering where you think that might happen, where you might meet those people to develop those relationships?”*

SU3: *“In a way it could be here, it could be at your local gym, I don’t know, somewhere... But not on the streets cause you don’t know what might happen. You’ve got people who are out there selling drugs, someone could be a lesbian or whatever. I mean a lot of people who are on drugs has got a problem, like a crack or heroin addiction... I mean you’ve got to be aware of these dangers because these people can actually put you in an unsafe environment.”* (847-857).

Concerns with safety and protection could also be seen in the structure of the building – as if the centre itself might be vulnerable to the outside world. I observed metal shutters which were attached externally to the windows and doors, large security lights which were encased in rusty cages and a metal fence with sharp ‘forks’ at the top of each post presumably to prevent people from climbing over them. In addition doors contained safety glass and had additional security locks which served to prevent ‘unauthorised’ access. Some of these physical features also served to restrict the movements of service-users – to keep service-users in the centre, perhaps as a means of protecting service-users from external threats, and to ensure continuing observation. Indeed there was evidence of this as I shall discuss later.

## **1.6 Authority**

A sense of staff-members’ authority over service-users was conveyed in the data. This could be seen in accounts where service-users asked staff for permission to do

certain things: *“He’s saying to me, ‘Oh can you take Jenny with us on the walk?’ and I just say ‘I can’t because we’ve got enough, there are enough of us to go on it, it would just be too much to take another person’”*. (SM4, 214-216). Another staff-member commented on the changes that the service will face in coming years and commented: *“I have this horror of being with my little group and them saying ‘can we go swimming?’ and I have to say ‘No, sorry lads, there are only six who can do it and there’s ten”* (SM6, 202-205). These extracts demonstrate an acknowledgement of ‘rules’ about actions that are or are not possible to take within the centre. These rules limit and override the choices that can be made by both staff and service-users. Though authority could be a feature of relationships between staff and service-users, it also appeared to be a feature of staff-member’s relationships with others within the service system, as will be discussed later.

In the following extract a staff-member talked about the closure of residential homes and the impact that it might have on service-users’ relationships. In her talk she notes the authority that family or carers often have in relation to service-users:

SM4: *“It’ll just be a right shame cause a lot of them have known each other for years and they’ll probably just end up getting split up. A lot of them have got girlfriends and boyfriends so they might end up getting split up as well”*

Researcher: *“What do you think might help with that? Is there any way people might not get split up or might still manage to keep the relationship going?”*

SM4: *“It’ll be alright if the family or the carers made a point of saying to them that they could meet up maybe one night or twice a week or whatever”*.



### Reflexive Analysis – Questions about difference

In the preceding extract there is an assumption that families and/or carers have the authority to allow (or not allow) the continuation of the relationship. The above example also demonstrates how at times I struggled to adopt a questioning style that simply tried to uncover participants' ideas about relationships, and instead moved into a style of questioning that I sometimes use in my clinical work – one that I hope might prompt somebody to think about the potential for different ways of doing things, rather than just passively accepting the status quo. In the above example I felt that staff might have used their authority productively – to actively work to maintain and support service-users' relationships.

The authority the staff-members had over service-users was also reproduced the observations that I made, for example in the fact that staff-members carried keys and were able to access rooms in the centre which were locked to service-users. Similarly, staff had access to the codes which would allow them to pass through doors which separated the inner area of the centre from the entrance and exit. As I observed service-users leaving at the end of the day I noticed that a number of service-users came up to the door then knocked to gain the attention of staff who would then open the door and let them through. It struck me that many of the service-users would certainly have the cognitive capacity to remember the five digit code, and so this particular physical feature of the building seemed to serve to restrict the movements of service-users. During the course of this research I was also invested with this authority usually afforded to staff, as I was given the code to the door, which gave me the freedom to enter and leave the centre as I wished.

### Reflexive Analysis: Authority and Me

In undertaking this research I had at times a heightened awareness of the authority that service-users seemed to invest in me. For example after one interview I made the following entry into my reflexive diary:

*I interviewed [name of service-user] today. I felt really uncomfortable at the end of the interview. He was sat, perched on the edge of his chair as if ready to leave but did not leave. He looked at me expectantly. I had a strong sense that he was waiting for me to give him permission to leave the room. Thinking about this made me realise that I had had this same sense before – when meeting with other service-users to go through the consent process, or when I've interviewed other service-users. The endings of service-user interviews feel very different to the endings of staff interviews. Staff say 'Bye' and stride out of the room as soon as I've finished or else they stay a while and initiate conversations about other things.*

The example described above relates to a 'feeling of authority' that I experienced with conscious awareness at the time, and which may have drawn my attention to issues of authority within other relationships. On another occasion though I again had a conscious awareness of how a participant related to me 'as-if' I was in a position of authority (by asking my permission for her mum to come to the centre), but was unaware until I examined the interview transcript that in my response I reinforced the construction of staff having authority. I realised that I had tried to reject my authority but had done so on the grounds that I 'was not staff' and in doing this I reinforced ideas that staff working at the centre were authoritative and had the right to direct what actions were and were not possible:

SU5: *"My mum might come here"*

Researcher: *"Your mum might come here?"*

SU5: *"Mmm, will that be alright?"*

Researcher: *“Er, I suppose it’s not for me to say because I don’t work here”*. (395-398).

At this point in the exchange I became more conscious of the power dynamic between us, and tried to explore this further.

Researcher: *“Why is that you ask me if it’s OK?”*

SU5: *“I don’t know. Because you’re here”*. (398-399).

In this case the participant’s difficulty in answering my question might point to the fact that this dynamic is so prevalent and therefore ‘taken-for-granted’ in her relationships with others that it becomes difficult to recognise and articulate.

## 1.7 Aggression

Aggression appeared as a feature of relationships in a number of accounts. Two service-users spoke of experiencing aggression from other service-users: *“One of the lads started being funny with me and said he’s going to hit me”*, (SU1, 44), *“As soon as I had dried my hands he got hold of me and threw me out”* (SU3, 761-762). One service-user spoke of aggression within familial relationships. In this instance aggression seemed to serve as a display of masculinity and of maintaining the ‘male hierarchy’ of the family. He described his dad and oldest brother as being *“the boss”* (SU3, 418) and said that in time, as older men in the family died, it would be his turn to be the boss. He went on to say that the boss would get to *“throw his weight around”* (SU3, 425), and that this could be *“in a good kind of way or a bad kind of way”* (SU3, 429). A good kind of way involved *“stopping arguments”* (SU3, 431), whilst a bad kind of way involved *“shouting abuse and violence”* (SU3, 432).

Staff also commented on the potential for service-users to be aggressive:

SM1: *“You know you’re looking out for the other service-users as well... He has been aggressive towards his mum. If the relationship with the service-user gets so far here he’d become aggressive towards them”*. (325-328).

Another staff-member also commented on a service-user’s aggressive behaviour and said: *“He was taking his belt off and threatening them with it”*, (SM2, 908).

In addition the capacity for service-users to be aggressive, even if they had not acted aggressively before was noted: *“Somebody warned me that there was going to be trouble cause Donna’s noticed this and Donna’s going to thump her.”* (SM6, 557-559). This staff-member went on to say: *“She’s not actually thumped somebody but she is quite big, and I think there was a feeling that she might go and assault the other person”*. (SM6, 561-562).

During one of my observations at the centre, I watched a female service-user leaving the centre at the end of the day. She carried a lunch-box in her hand. As she made her way towards the door I noticed her look towards a nearby service-user and then shake her lunch-box in the direction of that service-user. The female service-user’s brow was furrowed as she made this movement, but she made no noise. The other service-user appeared oblivious of her presence or her actions and the female service-user then exited the building with no further consequence. I was struck by how difficult it was to determine what was meant by this action. It could be interpreted as an act of aggression, but could also perhaps have been an attempt at communication – perhaps a ‘goodbye’. There was no doubt as to the meaning of the action in the mind of a staff-member who was also present. He commented to me: *“I’ll interpret that as a non-friendly action”*. Just before I left the centre that day the same staff member referred to the behaviour again and stated that it involved *“real hatred”* and was *“nasty stuff”*.



## 1.8 Belonging

References were made to service-users and staff belonging to each other. For example staff referred to service users as being “*ours*” (SM1, 33). Another staff-member referred to forthcoming changes to the service and how the centre was going to “*get*” (SM2, 840) people with more profound disabilities. Another staff-member made the following comment: “*You know you need to account for people. You need to know where all your people are at all times*”. (SM3, 210-211). Service-users too, expressed ideas that staff belonged to them in some way: “*Gav is my staff*” (SU5, 484).

Belonging was also a feature of other relationships – one service-user showed me a greeting card that had been given to her. The message inside concluded with the words: ‘from your boyfriend’.

## 1.9 Empathy

In addition to sharing experiences and interest, relationships could also be constructed as involving empathy – identifying and understanding another person’s feelings. In the following extract the service-user left the room to get a drink. When she returned she talked about another service-user that she knew who had been crying. I asked her how she felt when she saw that he was upset:

SU5: “*I get upset as well. I get upset inside me.*”

Researcher: “*You get upset inside?*”

SU5: “*Mmm*”

Researcher: “*Why do you think that is?*”

SU5: “*I don’t know. It’s just a feeling. When he gets upset, I get upset*”. (198-203).

Another service-user demonstrated understanding of a friend's concern for her as they attended a funeral: *"I got up from my seat. I said 'I'll be alright Molly, Don't panic'"*. (SU4, 419-420).

### **1.10 Routine**

Some participants spoke of routines that were performed as part of their relationships. Relationships as routines were stable, predictable and might appear to be mundane to an outsider; however they were evidently important to participants. One staff-member talked about how she and a service-user had developed a routine for greeting one another, which overcame the obstacle of them having different verbal abilities:

*SM2: "He'll just come up to me and he'll just turn around and stick his bum in my face and stand there. And he wants his pinny fastening, so I fasten his pinny" (506-508). "Then he grins and goes off and does whatever he does. To me that's like him and me saying 'Good Morning! Did you have a good evening, are you alright?' 'Yeah I'm fine, are you Tony? Are you fine? Did you sleep well?', and to me that's like that" (510-513).*

One service-user speaking about her relationship with her boyfriend commented: *"I always phone him up at the weekend, on Sunday. I do it one week, he does it the other week"*, (SU2, 36-37). Another service-user spoke about his friendship with another service-user and said: *"He'll be sat with me, he'll dig out some of his chocolate biscuits, and he always gives me one"*, (SU1, 349-350).

As I observed the process of service-users leaving the centre on a Friday afternoon I saw routines enacted as service-users said 'goodbye' to one another and wished the other party a nice weekend. These acknowledgements were made with easy familiarity. They could also be initiated by staff. As I observed this process I felt that there was genuine warmth and reciprocity in the process. There were also other

routines evident in this process, for example I observed staff leading groups of service-users out of the building and towards waiting mini-buses. The staff carried clipboards, on which there appeared to be a list of names. The function of this appeared to be to chart which service-users had left the building and which bus they had boarded. I gained an insight into the anxiety that might be felt by staff if the familiarity of routine was threatened. One staff-member commented: *“You have steam coming out of your ears at this time of the day, sometimes you don’t get the right information of who somebody’s picking up, or else you get the wrong name”*. He then laughed whilst shaking his head and shrugging his shoulders, which seemed to communicate a sense of futility and frustration.

### 1.11 Physical Attraction

Relationships could also be constructed as involving a physical response to another person. In one interview a service-user discussed her relationship with her boyfriend:

SU5: *“I kind of get all excited with him”*

Researcher: *“You get all excited with him.”*

SU5: *“Mmm. Just seeing him”*.

Researcher: *“Just seeing him makes you feel excited.”*

SU5: *“Yeah. Giddy, giddy, giddy. I get giddy feet”*. (552 – 556).

Other service-users also spoke of feelings of physical attraction towards their partners:

SU2: *“We always sit together at dinner time. He’s so gorgeous. He’s good-looking.”*

Researcher: *“You think he’s good looking?”*

SU2: *“Yeah he’s too sexy with me (laughs)”*.

Researcher: *“Too sexy. Can you tell me what that means?”*

SU2: *“Erm... I’ve got some more photos of him. In my bedroom. I’ve got loads of him. In a drawer more photos”.* (316-321)

In this example, the service-user appeared reluctant to discuss what she meant by “too sexy” with me – this may have been because of the research context and the fact that I was a stranger, or it may also have been because she felt embarrassed or ashamed about her feelings; alternatively perhaps words were inadequate to express her feelings. Difficulty in talking about physical feelings was also apparent in another interview:

Researcher: *“What sorts of things did you and Chris used to do?”*

SU4: *“Sometimes I’d go to his bedroom. Sometimes he’d put his video on. Sometimes he’d sit down near me and put his arms around me, and he’d give me a kiss, on my lips”*

Researcher: *“How did that feel?”*

SU4: *“Alright”*

Researcher: *“Alright? Any other feelings?”*

SU4: *“No”* (SU4, 454-461).

## 2 *Discourses*

In this section of the analysis I considered the various different constructions of relationships and how they might relate to particular discourses. Discourses draw on the language of cultural and state institutions, which gives particular constructions meaning and power. Discourses of people with LD as being ‘childlike’ and/or abnormal were identified. These discourses are particularly powerful and are linked to institutional power as will be discussed later. Some alternative discourses were also identified which recognised the inequity and disadvantage experienced by people with LD, but which offered a more compassionate conception. A further discourse relating to love and romance was also identified which seemed to be the



dominant discourse used by service-users in their constructions of intimate relationships.

## 2.1 The Eternal Child

Various constructions utilised by staff (and at times service-users) could be understood by drawing on the discourse that people with LD are childlike. This was done with reference to their being dependent, naïve and requiring guidance and control by a responsible adult. This discourse was often marked by ‘parental’ overtones, which were sometimes explicit and sometimes implicit:

*Researcher: You were talking about your relationship with Stefan – I’m wondering whether you see any similarities with any other relationships that you might have, or that people that you know might have. The type of relationship that you have with Stefan?*

*SM3: Well I have a daughter and a son. My son is twenty-one and is away at university, my daughter is just about to do her GCSE’s. It’s not the same type of relationship, it might have been years ago. I don’t want to belittle Stefan by comparing him with children but I suppose it is inevitable that the caring aspect of that would slightly... yeah you are responsible for people and you want to make sure that they’re going to be safe”. (233-242).*

In this extract the staff-member shows some resistance to invoking the discourse of people with LD as being childlike, though he does use it and this may point to a lack of alternative available discourses. This tension can also be seen when the same staff member describes his actions towards the same service-user as “*Not quite mothering, but...*” (SM3, 160).

Teachers in the educational system may also be thought of as having responsibilities over children in the absence of their parents - and this idea was also conveyed in the

data: *“So I suppose it’s a bit like being a teacher back in class although we’re not in school they are like my class. People who I have more responsibility for, above the ordinary responsibilities for everyone else here”*. (SM6, 28-31).

Denial of sexuality is another means by which people with LD might be construed as being ‘childlike’. Comments which encompass that belief also contribute to a discourse that views people with LD as being childlike. In talking about a service-user’s romantic relationship one staff commented: *“There’s no sort of outwards signs that it could be anything other than what it is at the minute and that’s a kiss and a cuddle, holding hands and big hugs”* (SM3, 643-645).

A further way in which ‘childlike’ constructions were evoked, were in the sorts of experiences that service-users were exposed to. One service-user told me that her mum was organising a birthday party for her:

Researcher: *“Can you tell me about your party? What’s it going to be like do you think?”*

SU5: *“I’m going to have a clown”* (246-248).

Another service-user showed me a photograph of her next to a man in a ‘Santa Claus’ suit: *“That’s me with Santa Claus. That Christmas Fair we had here”* (SU4, 22). The photograph had been taken at the day centre.

Within modern western society, constructions of childhood are enshrined in ideas about innocence, protection and ‘good’ parenting which obligate particular actions. These ideas and actions are embedded in media representations, and in state, moral and religious discourses. The power of this discourse is therefore closely linked to these ideas and practices, thus when a ‘childlike’ discourse is invoked it may be very difficult to subvert its influence.

## 2.2 Abnormal

Historically, there have been discourses available which mark out people with LD as lacking 'normal' human attributes, and which thus mark them out as being deficient or different in some way.

At times staff seemed to utilise this discourse in statements that separated service-users from others: *"I think it's nice for them to get out and just mix with the general public"*. (SM4 338-339). In this example service-users are not classed as being part of the 'general public'. Similarly in the following extract a staff-member differentiates service-users from 'normal people': *"It's great because people, especially the slightly older and the very older people that you meet out walking, they talk to them as normal people"*. The use of the word 'as' in this example belies assumptions that in fact service-users are not 'normal'.

One staff-member talked about some older service-users as having not met 'people' before. This seemed to differentiate 'people' from the individuals that service-users would certainly have come into contact with including other service-users and staff:

*"At the moment we're trying to integrate them into the schools so that younger people that are coming along are aware, so they've actually met people but you have that gap where they didn't and they've not had any meeting with people"*. (SM5, 239-243).

In one interview a service-user repeatedly described herself and that ladies that she lived with as being *"special people"* (SU6, 124), suggesting that she viewed herself and those she lived with as being fundamentally different to other people who did not attend the day-centre or live in staffed housing.

Discourses of abnormality pathologise difference and suggest a qualitative difference between those categorised as 'normal' and those categorised as 'abnormal'. These discourses are rooted in historical ideas about the origins of LD.

In times both mental illness and LD were attributed to supernatural causes, demonised and considered to be the province of philosophers and priests (Neugebauer, 1996). Those who were considered to fall into such categories were thought to be lacking in morality and were feared. Such ideas grew more powerful in the late twentieth century when fear and moral approbation led to initiatives to incarcerate those labelled as having LD, as means of protecting society. In the current study the use of discourses of abnormality was not explicitly linked to immorality, though the availability of these associations were sometimes marked by staff's recollection of previous experiences with people with learning disabilities, or of stories that they had been told. In the following extract a staff-member talked about what he had been told as a child about a large institution for people with learning disabilities:

*"We were always warned 'you mustn't go near the hospital' because there were people there who were different, and we had no idea what these people were like".* (SM6, 76-78).

### **2.3 Romantic**

Romantic discourses about relationships and 'being in love' dominated service-users talk about their actual or anticipated (and exclusively heterosexual) intimate relationships. Within a romantic relationship ideas about 'love', 'monogamy' and 'marriage' prevailed. Romantic discourses were evident in service-users' talk but were also represented in the articles that service-users brought to show me (cards, photographs and gifts), and in the activities and physical decoration of the centre as Valentine's Day approached.

One participant showed me her and her partner's engagement rings which symbolised their commitment to one another and intention to marry. Speaking of her fiancé she commented: *"He's my future"* (SU2, 171). Another service-user showed me a photograph in which her and her boyfriend had dressed up in wedding



clothes and posed for the camera. She told me that after the picture had been taken he asked her to marry him: *“He asked me nicely, he was smiling at me. He said ‘I want to get married to you Jane, a proper wedding’. I said ‘Yes I will Chris, because I love you’”*, (SU4, 412-415). She also showed me a greeting card which had a red heart on the front. Inside the message stated: *‘Dear Jane, I am missing you very much and I love you very much’*. Further evidence of romantic discourses could be seen as the centre prepared for a ‘Valentines Disco’ and garlands consisting of chains of red hearts were strung around the centre. One service-user showed me some Valentines cards that she had received. I noticed from the sticker on the back of the card that it had been made at the centre and sold in the centre’s ‘community shop’.

Romantic discourses about relationships often assume that one of the functions of such a relationship is to raise children. Interestingly, this aspect of a relationship was commented on by only one service-user: *“You could grow up with your girlfriend, children... You want to grow up, get a job, get respected, get a house, and raise loads of children because those children are the next generation”*, (SU3, 857-862).

One service-user talked about having more than one boyfriend which might be viewed as a challenge to the romantic discourse; however her use of the word ‘story’ in describing this to me (*“I’ve got a love story going off with my boyfriend... I’ve got two boyfriends here”*, SU5, 10-13) appeared evocative of the ways in which romantic relationships are often presented in the media. Plotlines of films, books and television series often involve some sort of challenge between two characters for the love of another and the conclusion of the story is the resolution of the conflict, with one character ‘winning the heart’ of another. As the interview continued she clearly expressed preference for one of her two boyfriends, and introduced the possibility of them marrying:

SU5: *“We met in here for a couple of weeks. Then he decided to get married to me.”*

Researcher: *“He decided to get married to you?”*

SU5: *“Yeah, I don’t believe it!”*

Researcher: *“What do you think about that?”*

SU5: *“I think it might be alright”.* (561-566)

Romantic discourses are closely linked to the official recognition of heterosexual relationships in law and in religion. This discourse is powerful as it draws on the language and ideas enshrined in these institutions. The absence of alternative discourses however is notable and worthy of further consideration.

## **2.4 Misfortune**

Some alternative discourses were employed with staff which moved away from categorising service-users as being childlike, or inhuman. In these discourses, behaviour that might be considered to be unusual was understood with reference to discrimination, mistreatment and/or oppression rather than a reflection of some inherent internal characteristic:

SM5: *“Some people have certain habits and you think ‘Well why do they behave like that?’, and it’s only when you hear that if they did something wrong, they’d be punished that they were probably not spoken to in a very nice way [ ] It’s only when you’ve heard that you realise why some people do certain things”* (152-159).

Other staff expressed ideas that service-users had the ability to participate in the same relationships, activities and experiences that other people take for granted, but that they had been prevented from doing so by the service-system:

SM5: *“It’s nice if they can go into a shop and actually buy stuff themselves but when somebody’s there saying Come on, come on, give me your purse, I’ll get your*

*money out' you know you're just taking away their little bits of independence from them"* (306-310).

In the following extract a staff-member talked about feeling sad when he heard about an older service-user who had been prevented from marrying a woman with whom he had a relationship with: *"Adrian was such an amiable guy, he probably could have married this woman. He probably could have had children with this woman"*, (SM6, 693-695). Talking about the same service-user, the staff-member went on to say:

SM6: *"He eventually got a flat with some friends from [local area]. He was in his sixties, seventies and he said to me 'I wish we'd done this years ago'. They were like three young lads in a flat, going to the pub together and they thought it was a great life. He suddenly realised they'd got it a bit late in life"* (702-706).

### **3 Action Orientation**

In this phase of the analysis I turned my attention to how different ways of speaking fulfilled particular functions for the speaker. I considered how particular versions were promoted over others (which might be directly referred to or implied).

#### **3.1 Validation through approval**

In some service-user accounts, the importance of relationships (particularly romantic relationships) being approved by others, was evident. In one interview a service-user told me that she and her boyfriend had spent the night before looking round a respite service that they were going to together: *"My mum and dad agree and like after Christmas we go there"*. (SU2, 15-16). Another service-user spoke of his desire to have a girlfriend. When I asked him what he thought it would be like if he did have a girlfriend he replied: *"My mum would be absolutely over the moon"*, (SU3, 658). It was also evident that it was important that staff accepted and approved of the relationship:

Researcher: *“I was wondering whether other people ever say anything about you and Matthew?”*

SU2: *“Judy, that’s our key worker. She knows.”*

Researcher: *“And what does she say about it”.*

SU2: *“Er, we’re doing OK. It’s fine with Judy. We’re doing OK”.* (SU2, 149 – 152).

One service-user spoke with some anxiety and frustration when describing the disapproval she encountered with regards to her relationship with her boyfriend:

SU5: *“I can’t split up with John. [name of staff-member] wants me to split up with John.*

Researcher: *“Who wants you to split up with John?”*

SU5: *“My centre does, but I can’t. How can I?”*

Researcher: *“Why do they want you to split up with John?”*

SU5: *“It’s because me and John get closer and closer and closer”* (592 – 597).

Whether a relationship was approved of or not, had implications for ways in which the relationship was either facilitated or constrained in its development, thus approval was closely tied to power.

### **3.2 Appeals to friendship and family**

A number of staff referred to their relationship with service-users as being a ‘friendship’: *It’s just like normal friendships really, isn’t it?”* (SM1, 62). *“It’s like twenty years I have been a friend to somebody, I know it’s in a professional situation but we are still friends me and Tony”.* (SM2, 751-753). Other staff likened their relationships with service-users to those they might have with family members:



SM4: *“The staff are very good here. They are very welcoming and they are all really friendly but the service-users are really friendly as well and they are very welcoming and as I say the feeling that they give to you it is just like being in one big family as opposed to being in a workplace”* (97-100 ).

It was very difficult to reconcile the use of these definitions with the ways in which the relationship was constructed, which tended to emphasise staff-members’ power and influence in the relationship with that of service-users being limited. The function of talking about relationships in this way may be to minimise conflicts and differences in power, and to imply that the relationship is equitable and harmonious. It might also serve to portray the speaker as a good person – as somebody who puts their whole person into their work, and who is good at their job because of this. Interestingly though some service-users spoke of their relationships with staff members, none described it as a friendship or familial relationship.

### **3.3 Emphasising expertise through concepts of time**

Many staff highlighted the importance of building up relationships with service-users over time. This served to mark their own knowledge as being ‘special’, of the skills and expertise needed to understand service-users, and of the difficulties that might be encountered by ‘less experienced’ people. In doing so utilising this device also highlighted the ‘different-ness’ of the service-users they worked with. This is illustrated in the following extracts:

SM2: *“I’m mentoring this student and I’ve seen him interacting with clients and I’ve said to him [ ] ‘Look, you know that’s not appropriate what you’re doing, like banter’. I said ‘That’s not appropriate... it takes years and years to be able to know who you can and who you can’t have a joke with’”* (252 – 256).

SM1: *“New people coming in are a bit unsure about speaking to the service-users, they probably hear us and think ‘Oh my God they talk to them like that’, but it’s*

*because you have that relationship, it takes a while to get that relationship with them” (52-55).*

Similarly, some staff promoted their present accounts by comparing them with constructions that they might have held at an earlier point in their life when they were more naïve. This served to highlight how their ideas had changed as their experience and expertise increased, and so these accounts worked to emphasise the speaker’s competence:

SM1: *“I suppose when I first started going in [to the hostels] and if I went to reviews or anything, you kind of expect to have that relationship with them but you just can’t because there is that barrier there and I think you get used to it” (191-194).*

SM6: *“I suppose gradually in the early years there was a brief period I suppose when I got to realise that people were the same as me...I suppose to be honest when I started because people were portrayed as being different here it took me some time to adjust”. (111-114).*

### **3.4 Managing Responsibility**

Staff accounts of their interactions with service-users often suggested that service-users were unable to take responsibility for their choices and actions, thereby justifying staff-members taking responsibility for them:

SM1: *“It’s a matter of being able to assess a situation before it gets out of hand, before they get too upset. You can sort of analyse the situation before it gets to that and then you know you’re able to defuse it and lead them on to something else” (68-71).*

Another staff-member relayed a story of how somebody pushed in front of a service-user as she was queuing to be served; she claimed that the service-user was unaware of what had happened but stated: *"I was annoyed. Very annoyed... In fact I think I walked Samantha in front of her and put her in front of the queue. I did actually"* (SM4, 398-399).

At other times however, staff de-emphasised their own responsibility for acting in particular ways, and instead located that responsibility with either service-users or other parts of the service system. Responsibility was sometimes attributed to service-users for being or acting in a particular way (which might be conscious or unconscious), which then compelled staff to respond in specific ways. In the following extract a staff-member described his response to the 'games' that a particular service-user played with him: *"He knows I'm eventually going to find where he is and he does play games really. So in a way he does have control over me because of what he does"*, (SM3, 203-204). This extract portrayed the service-user as an attention-seeking 'naughty child' and links with discourses of infantilisation.

At other times responsibility for particular ways of interacting with service-users, was ascribed to others in the 'system'. In the following example one staff-member talked about the limits imposed by managers regarding what activities he could do with service-users: *"My boss' boss said 'no we're not doing that', so again it seems silly. I didn't want to do it but if people want to do it, it seems great. But yes there is that from above as well, I think the managers"*. (SM6, 278-281). In this extract the notion of hierarchical authority and of the limits imposed on staff is introduced.

### **3.5 A Joint Engagement**

A further way in which staff strengthened their version of events was through a subtle appeal that others would concur with their account. This could be seen for example in their use of the pronoun 'we', suggesting that their understanding and

actions were not idiosyncratic but shared with others. *“It wasn’t until it first came to light that she was staff...we realised that it’s probably a problem”*, (SM1, 362-363), *“We try to do things for people that will improve their lives really”* (SM6, 184-185). There is a great deal of power in a collective view – it resists challenge, acknowledges a particular subject position, and carries with it expectations of particular forms of actions and not others. This ‘shared understanding’ was also apparent in the way staff used the pronoun ‘you’ rather than ‘I’ when referring to their actions and/or experience – which reinforces the idea that anybody in their position would act or feel accordingly. *“You really notice it when you have a few days off and the greetings you get when you come back”*. (SM4, 39-40). *“You know you’re always looking for new ways of working and if it’s not proving satisfactory or successful then you would change the way the relationship’s working”*. (SM3, 266-268).

#### **Reflexive Analysis: Invitations In**

The way in which participants used the word “you” in this way might also be viewed as an invitation for me to hear what was said in a particular way, in a sense, an invitation for me to be ‘like’ staff. Participants were aware of my status as a clinician, and in my interactions with staff *and* service-users over the course of doing this research I noticed a number of different ways in which people seemed to orient to me ‘as if’ I was a staff-member. For example in the way that some service-users asked my permission for things, and in ‘privileges’ I was afforded that were usually reserved for staff. There were also features of my behaviour which on reflection are likely to have contributed to others experiencing me as being ‘like’ staff – perhaps my autonomy over the research proceedings in particular.



### 3.6 Claiming status and ability

Presenting oneself as being accomplished in various spheres of functioning appeared to be one of the functions of some service-user accounts. In doing this, participants promoted versions of themselves as being 'like others': "*Can do that, we can do meals, cooking, we can do that*". (SU2, 180 – 181).

Another way in which service-users presented themselves as being 'like others' was in their adoption of gendered stereotypes and activities. A number of female service-users described their competence in domestic activities: "*And sometimes, 14<sup>th</sup> of February, it's Valentine's Day, sometimes I do a romantic dinner for him*" (SU2, 120-121), "*I've got a new job. Change the bed clothes, do bathroom cleaning, clean the bath, clean the toilets, and that's my job. Very important job. Keeps you busy, got a lot of things to do*" (SU6, 4-7). One of the male service-user participants drew on stereotypical notions of male dominance and aggression, and in doing so allied himself with his father and brothers. In the following extract this service-user showed me a family photograph:

SU3: "*If you mess with my dad [service-user points to his dad in the photograph], you mess with this big boy [points to oldest brother], and if you mess with my dad and him, you mess with him [points to another brother], if you mess with them three you mess with him [points to another brother], and if you mess with them four you mess with me. I'm the fourth oldest*" (304-312).

A desire to be "macho" was commented on by one staff-member who spoke of how a particular service-user related to others. This machismo however was presented as something that was desired but not obtained:

SM3: "*I think he probably sees himself as being bigger than himself, and he wants to be a big macho man sometimes. It's not just towards me it's towards other members of staff as well, like wanting to arm wrestle people*" (322-325).

Three service-users brought in photos to show me, and many of these showed them participating in ‘ordinary’ culturally valued activities, such as holidays and birthday celebrations. A number of participants also talked about formal celebrations when they had been called upon to undertake a role involving exceptional status. For example one participant showed me a photo of herself in a bridesmaid dress: *“That’s me. I was bridesmaid”* (SU4, 52). She also showed me a number of other pictures of herself taking part in various aspects of the wedding, such as throwing confetti over the bride and groom. Another service-user showed me pictures of his brother’s wedding and talked about his brother asking him to be best man at his wedding: *“My brother wanted a best man and he came to me first and said ‘Will you be best man?’, I said I would”* (SU3, 596-596). Another service-user described attending the funeral of somebody close to her, and of her singing a song at the funeral.

### 3.7 Appeals to Togetherness

Two service-users described long-term romantic relationships. These descriptions seemed at times to fulfil the particular function of achieving ‘togetherness’ – emphasising their unity and status ‘as a couple’ rather than as individuals: *“Tuesday, I stay with him on Tuesday, do rugs, go to my work together, and Friday doing them things, curling doing that together”* (SU2, 65-67). This togetherness was also evident in the physical closeness of the couples and this was pointed out to me as we looked at photos: *“That’s Matthew, and that’s me. Yeah with his arms around me”*. (SU2, 101). Another service-user showed me a photograph of her and her boyfriend cuddling: *“That’s me and Chris, he’s giving me a cuddle or a kiss”* (SU4, 64).

In one interview I was shown numerous photographs of the service-user with her boyfriend, and as each one was presented in turn the service user pronounced: *“This is me and Chris. Together!”* (e.g. SU4, 184). I was struck by the tone in which she

pronounced the word 'together' which seemed to me to be both joyous and triumphant.

#### **4. Positioning**

Participants' accounts suggested that there were a range of subject positions available within talk of interpersonal relationships.

##### **4.1 Naïve versus Knowledgeable**

In some accounts, staff-members emphasised their own superior knowledge as compared to service-users' naivety:

SM1: *"He can misinterpret quite a lot of what a relationship's about. You know like friendships and things like that, he might think the relationship's a bit more, like more of a sexual relationship". (242 – 245).*

One staff-member talked about the impossibility of a service-user being able to fulfil his wish to marry his girlfriend. When I enquired why this was so he replied:

SU3: *"Well there's things like what their idea of marriage is, you know both of them have done some relationship counselling, we've done some relationship groups here, and some of the things that have come back from that are they haven't got the right concept of what marriage is all about and what a relationship in a marriage is about". (545-549).*

Another staff-member described how he was asked to intervene in order to make a service-user "realise" the status of his relationship with another:

SM6: *"Donna's carer said 'look, you better talk to Paul, because he needs to realise that he has this relationship with Donna. He refuses to believe it but we all think he does, and it's upsetting Donna". (477-480).*

Naivety is often a characteristic associated with children, and so this positioning is given meaning by invoking the 'eternal child' discourse. There is also some recognition of normative concepts of relationships, and so it also draws on discourses of abnormality.

#### **4.2 Dependent versus Responsible Carer**

Staff-member accounts pointed to the responsibility that staff had to ensure service-users' well being. Often this was named explicitly: *Obviously he's in my group and I am responsible for him*" (SM2, 463-463), *"Well you feel quite responsible for people"* (SM3, 215). Positions of responsibility were also engendered in the way staff described how service-users, and others within the system related to them: *"I'm the person they would come to if they had a problem. Or not even a problem. If they wanted to go to college or something like that, they would come to me. And similarly if there was any concerns about them the manager would come to me"*, (SM6, 28-31). Another staff-member speaking about service-users said: *"They are looking to you for things that they want to do"* (SM5, 64-65). There could also be degrees of responsibility – one staff member described his 'key group' as: *"People who I have more responsibility for, above the ordinary responsibilities for everyone else here"* (SM6, 34-35).

Some staff spoke of their efforts to ensure the safety of service-users, thereby positioning themselves as acting responsibly. For example one staff-member described how he approached children who rode their bikes near to service-users as they were walking: *"You try and explain: 'Don't go dashing about with your bikes over the path in front of them cause they're unsteady. They could easily fall'"* (SM5, 361-363). Positions of responsibility were also evident in some of the other activities that staff participated in: *"I've been to his house, they had a meeting for him, like any changes that you can make in Garry's life to make his life better sort of thing"* (SM4, 563-564). In this example the staff-member is clearly identified as



somebody who may be able to suggest or make changes in Garry's life, which will benefit him. The extract also suggests that it is staff who have the knowledge and skills to do this, rather than Garry himself.

One staff-member highlighted a dilemma he experienced when service-users approached him with some complaint, but he felt limited in his ability to influence the situation: *"It's difficult when people have come up to you and said 'She's not my friend anymore and I'm really upset about this' and you know what can I do? It's difficult you can't control people and people's emotions. It's difficult to counsel people in those incidences"*. (SM3 489-493).

In one account it was apparent that the role of 'responsible carer' was also one that could be taken up by service-users. One service-user spoke of the relationship that he had with another man who lived in his residential home. He described how this man had difficulties in walking and how he tried (in various ways) to ensure that he was "alright".

Researcher: *"What sorts of things do you and Ian do?"*

SU1: *"Well I just pop my head in to see if he's alright, and if he's alright I probably just leave him. Probably go back before he goes to sleep and see if he's alright"*. (SU1, 212-216).

In this latter example the positioning of this particular service-user as a responsible carer raises a challenge to dominant discourses that position people with learning disabilities as being dependent and childlike.

### **4.3 Controller-Controlled**

At times, service-users evoked descriptions of staff as being in control, and of themselves correspondingly as being out of control. In the following exchange a

service-user described what it felt like and what happened when she became ‘wound up’.

SU5: *“I climb completely. I climb up, completely up.”*

Researcher: *“What’s it like when you climb up?”*

SU5: *“I start going up in the air again. I start doing it”*

Researcher: *“What’s it like when you go up in the air?”*

SU5: *It’s OK because I’m at the centre.*

Researcher: *“It’s OK cause you’re at the centre? Why is it OK at the centre? What happens at the centre?”*

SU5: *“They try to calm me down. They try walking down there”. (463 – 472).*

Similarly, in another interview I asked a service-user about how long she had lived in her current home. The response suggested that the length of time that people spent in the home was related to their control or lack thereof:

SU6: *“They always keep them a little while to keep out the trouble”*

Researcher: *“Keep out the trouble? Em, what sort of trouble?”*

SU6: *“Well to keep out the trouble, to make them controlled, to make sure. If you keep them safe a long long time to make sure”. (120-124).*

Staff also positioned themselves as being ‘in control’, and this often evolved from marking themselves out as being knowledgeable and responsible people. Odd or disturbing behaviour was individualised and construed as requiring expert action, and was therefore linked to discourses of abnormality. This made staff indispensable as the people who can ‘manage’ this behaviour. Others (such as family members or more junior staff) could be positioned as not being able to take a position of control.

SM1: *“He sees his mum less ‘cause of the abuse. She used to have real problems when he went home. I think she was going to try and visit [name of residential home] and see him there, so there’s staff around and what have you.”* (402-405).

The position of being in control might be taken up by staff, or they might be positioned by others: *“My key worker mentioned it, he said Garry’s troubling again, he’s in a bad mood. Just try and calm him down”* (SM4, 540-542).

There were also however examples where staff referred to *their* actions being controlled by others; for example carers, managers and society. In the following extract a staff-member talked about staff supervising service-users: *“I think also we are maybe a bit frightened of not being seen to do our job. I think there’s a slight sense of paranoia sometimes that we must be supervising people. Else if something goes wrong someone will say ‘Well where were you Dave?’”*. (SM6, 223-227).

#### **4.4 Part of a Partnership**

In talk about their relationships, some service-users clearly positioned themselves as ‘part of a partnership’. This partnership could be a dyad as in romantic relationships, or could involve a group of people (for example a group of service-users). In doing this they emphasised working together, and mutual responsibility to achieve some common aim. When discussing her future with her partner one service-user commented: *“Independent living is like doing your own cooking and washing and go shopping...get out more... I want to do that with him. He’ll have to learn to do something to help me. He wash up and I’ll dry up.”* (SU2, 178-180).

One service-user commented on his brother’s relationship with his girlfriend, and contrasted this with how he imagined he himself would behave if he too had a girlfriend:

SU3: *He treats his girlfriend like a doormat. She's hygienic and she does the washing up, and all the cooking. She orders Chinese, she carries on doing everything and he just lays back. He doesn't do nothing. If I had a girlfriend I wouldn't do exactly the same, I would have helped my girlfriend*" (731-735).

One service-user described how she and the other ladies that she lived with worked together: *"The second job we do we always go to the shop to buy the drinks for people, for people to have a drink"* (SU6, 53-54).

## **5 Practice**

In this stage of the analysis I turned my attention to particular actions that were legitimised or denied through the particular discursive constructions that were utilised.

### **5.1 Supervision**

Constructions of aggression, vulnerability, naivety and lack of responsibility on the part of service-users point to a number of particular practices that staff-members are inevitably called upon to fulfil. In order to fulfil their responsibilities staff made reference to the need to observe, supervise and monitor service-users as is seen in the following extract where a staff-member had just described how she tried to protect a service-user from his own feelings about his relationships with others:

Researcher: *"And how do you do that?"*

SM1: *"Just keeping an eye on things. You can sort of monitor how he is"* (336-338).

Supervision also provided a means of ensuring that service-users behaved 'appropriately': *"For peace of mind I like to keep an eye on him"* (SM3, 158-159). In another interview a staff-member told me how a fellow member of staff had told



him that he'd "*better watch*" (SM6, 565) a particular service-user, who was "*getting wound*" (SM6, 561) by another.

In addition supervision could be seen to be enacted in the recordings that staff made about the locations and activities of service-users. For example as I observed service-users leaving the centre at the end of the day I noticed staff carrying clipboards and noting down which service-users had left and which bus they had got on to.

## 5.2 Communication

There was also an assumption in staff's talk that other people would also relate to service-users in a way that inherently involved their having some degree of responsibility, thus it became important to communicate details of service-users' experience and behaviour to others in such a position: "*He has a book, he had a diary and I write in what he's done*" (SM2, 534-535), "*We had to let the club know and say 'look it could be a bit of a problem there as well'*" (SM1, 364-365). The practice of communicating things about service-users is linked to the practice of observing and monitoring them. It also links to ideas about 'doing for', reflecting an assumption that service-users do not have the ability to communicate things for themselves.

Staff also described receiving similar communications from others: "*I was sort of warned – 'Watch if he takes a little strop about something'*" (SM4, 523-524); "*One day my manager said the college had been in touch because Paul, one of my group was being a bit silly with them*" (SM6, 38-39). Communicating in this way also enabled staff in the position of 'responsible' caregivers to respond to any 'aberrant' behaviour.

### 5.3 Control and Management

Supervision and communication was highlighted as being important in staff's accounts and through these processes they were able to intervene – to manage and control service-users' behaviour, to avoid difficult or distressing situations or to remedy situations that had already become thus, and/or to ensure 'appropriate' behaviour. It therefore closed down opportunities for service-users to act autonomously and find solutions to their own difficulties, and in doing so reinforced infantilising discourses. These actions also closed down opportunities for 'normative' (though perhaps distressing) experiences and emotions – such as the pain that the service-user described by one staff-member might have felt, given the opportunity to realise that his attraction to another person was not reciprocated: *“He just gets so confused with what a relationship is, it's just difficult for him so you have to try and just get in there and watch and monitor it and if it's getting out of hand just try and distract him”* (SM1, 348-351).

Similarly one staff-member described the need to keep service-users' feet 'on the ground' in order to protect them from potential disappointment in relationships:

SM5: *“Sometimes they can get a bit too carried away, expect a bit too much out of a relationship. You're always sort of a little bit careful that they don't build up their hopes too much because then if something happens, as it can do, you can arrange something and then you can't go and you see the disappointment and they really get down so you try to keep their feet on the ground all the time”*. (472-479).

Acts of control and management were enacted in interactions between staff and service-users. As I observed a group meeting taking place at the centre, I observed one member of staff saying *“Don't swear please”*, to a service-user. At a later point another staff-member instructed a service-user to *“Speak properly”* as he relayed his news to the group. Similarly as service-users left the building at the end of the day I observed one staff-member say to a service-user with some frustration: *“Come on. You're blocking the hall”*. All of these interactions occurred in an environment

where lots of other people were around. None invoked any response of surprise – it appeared that such behaviour was unremarkable given the relative position of the people involved. Indeed there was an explicit expectation from others that staff would manage service-users' behaviour: *“If he's carrying on or owt, people come to me and say ‘Judy can you come and deal with Tony?’”* (SM2, 464 – 465). Such comments may have evoked different reactions had they taken place between two other individuals, for example between two staff-members. It is the positioning of the staff member as somebody who is both more knowledgeable and responsible than the service-users, the construction of their relationship as involving guidance and authority and the use of a ‘childlike’ discourse that legitimises such actions.

Control and Management as a legitimate feature of relationships (particularly between service-users and staff) was vividly embedded in one service-user interview. In the following extract one service-user talked about relationships between staff (who are people who work in her residential home, as opposed to staff at the day service), and ‘ladies’ (who are the people who live in the home):

SU6: *“Cause the staff control, the staff's in charge, and they always control and look after them and they always behave all the time”*. (65-67), and: *“They've [the ladies] got to try to do what they're told. And they've got to be best behaving”*, (162-163).

### Reflexive Analysis – ‘Taking it for granted’

The above account given by this service-user had a ‘taken-for-granted’ quality about it – this was simply the ways things were and they couldn’t be any different. There was no hint of resistance to this control. I felt sad about this and tried to test out alternatives by asking the following question:

Researcher: *“What would it be like if somebody else was in control? What about if the ladies were in control, what would that be like?”*

At this point the service-user looked perturbed – her brow was furrowed and she shook her head. She replied: *“Staff are talking to ladies all the time and that’s what they do. It’s staff’s job to help the ladies, to keep people safe”*. (SU6: 70-71)

The power and influence that staff (and carers) had in enabling or limiting opportunities for service-users to further their relationships was also apparent:

SM3: *“One of the questions was what would you like to happen in the future. ‘I’d like to marry Lisa’. And then when I mentioned that to his carers they said ‘Well that won’t happen’ and I said ‘I know it won’t happen, but I’m just writing down what he said’”*. (539-541).

The example above points to an assumption that the service-users who are being discussed will not be able to fulfil their wishes, without the support and approval of important others (i.e. those who hold positions of responsibility in relation to them). There were other examples too of the impact on relationships that the service-system could have, and the powerlessness of service-users in relation to this:

Researcher: *“You were telling me there that you and Brian used to have meals together on the unit. Do you still have meals together like that?”*

SU1: *“No”*



Researcher: *"How come?"*

SU1: *"Well they switched me upstairs to a new unit"* (SU1, 63-67).

#### 5.4 Passivity

Another effect of service-users being positioned within discourses of immaturity, irresponsibility and dependency, was that it became legitimate for others to act on their behalf or 'do for' and opportunities to challenge this were limited. On a number of times I was struck by the lack of resistance that service-users appeared to demonstrate in relation to some of the limitations that were imposed on them. The following exchange occurred shortly after a service-user began to discuss her forthcoming birthday party:

Researcher: *"What other things do you think will happen at the party?"*

SU5: *"I don't know"*

Researcher: *"Who will go?"*

SU5: [shrugs shoulders] *"My mum's organising it"*

Researcher: *"Your mum's organising it? Who would you like to be there?"*

SU5: *"Who would I like to be there?"*

Researcher: *"Yeah"*

SU5: *"I don't know"*. (SU5, 253 – 260).

In another interview a service-user described what happened when she stayed overnight at her boyfriend's house:

SU2: *"I stop overnight and I sleep with Catherine"*

Researcher: *"OK, so if you stay overnight at Matthew's house, you sleep with Catherine, is that right?"*

SU2: *"Yeah"*

Researcher: *"Why is it that when you stay at Matthew's you sleep with Catherine?"*

SU2: *"Er, now they live in a bungalow"*. (108-112).

In this instance, I felt that the participant found it hard to answer my question and that that was because she could not contemplate that any alternative sleeping arrangements were possible. She continued our conversation by telling me that there were three bedrooms in the house and that each belonged to somebody. I was left with the impression that she had to sleep in the bedroom with her boyfriend's sister because there were no other bedrooms in which she could sleep.

## 5.5 Acts of Love

Within the romantic discourse there were opportunities for service-users to express their feelings of love for their partner, which might be done verbally or symbolically (for example in the exchange of gifts or cards, or in stereotypical experiences that might be expected of two people 'in love' such as having 'romantic dinners'. There were also expectations that feelings of love would be enacted in physical acts such as kissing and cuddling. In addition the 'romantic' discourse obliged partners to do things together and to be seen to be doing things together.

The 'romantic' discourse however might also close down opportunities for other forms of action. In participants' talk of intimate relationship there was no talk of disagreements or negotiation – it was as if the idea that such things might occur would be inconceivable, that 'love' intuitively guides individuals in how they must act towards their partner. There was also no sense that there might be any aspect of person's life that is not shared with a partner when one is 'in love', thus this 'romantic' discourse might close down opportunities for individuality. Importantly it might also close down opportunities to form other forms of intimate relationships that do not conform to the ideas demanded by the romantic discourse, such as same sex relationships, or relationships that involve no expectancy of marriage.

## **6 Subjectivity**

In this section of the analysis, I considered what the experiential impact might be, of being positioned in a particular way within a particular discourse. This process involves reflection upon what *could* be felt rather than what *will* be felt as discourse analysis holds that the effects of discourse may be unconscious. In some instances however, participants' accounts did reveal some consciousness of their positioning, and offered some commentary on how this impacted on their subjective experience.

### **6.1 Hopelessness and Powerlessness, Frustration and Futility**

The analysis of data presented here suggests that service-users may be positioned as people who are naïve to the 'real' nature of events, and who are dependent on others to guide them in 'appropriate' ways of being, to act on their behalf and/or to protect them from harm. This limits their opportunities for autonomy – to take control of their own life, to make decisions and to pursue goals. Feelings of hopelessness and powerlessness may ensue, resulting in apathy and a passive acceptance of the way things are, as was seen in some accounts. Alternatively, if one can imagine how things might be different – a better 'way of being' in the world, then there might be some desire to resist the way one is positioned, though the powerfulness of the discourse may make this unmanageable. One service-user spoke about his yearning for a different life:

SU3: *"We had a barbecue once and I said to my nephew, I said to him 'I don't understand how I'm so small, and how I have a bad heart and you're big and you have a healthy heart, you've got a girlfriend, you've got friends, you can do whatever you want and I can't. He actually broke down in tears and I regretted it"* (712-716).

### **6.2 Anxiety and Obligation**

Staff spoke of their positions as knowledgeable people and 'responsible carers' and of the need to be 'in control' which was achieved through supervision,

communication and management. The compulsion to take up these positionings, and to adopt particular practices came from discourses about people with learning disabilities, which view them as being childlike and/or abnormal. These discourses were experienced as being ubiquitous – existing in the ‘outside world’ inhabited by the ‘general public’, and reflected in expectations from colleagues, managers and others within the service setting. Staff therefore felt compelled to act in particular ways, and may have felt anxious about maintaining ‘control’ and managing the lives of those positioned in their care. Ironically despite the power and influence they experienced relative to service-users, staff may have felt powerless to act in different ways in the face of the expectations that were held of them. In the following extract a staff-member acknowledged the possibility of different ways of working, but the difficulties in achieving this:

*SM6: “We have this mania for supervising people. People here don’t usually attack each other and if there is a problem, people will normally find one of us, so I think sometimes I wish we had a bit less. We have to have some kind of supervision but we sometimes go a bit mad on that one I think. We have the base rooms covered with two people and I think maybe they could be there without members of staff. They could soon send for help if somebody had a seizure. Not many have seizures anyway so it’s not going to happen every minute. (SM6, 213-224).*

### **6.3 Pride and Esteem**

Being recognised as an individual who could contribute to and enhance the lives of others, enabled service-users to be liberated from the trappings of the oppressive discourses that had organised their lives, and experience relationships where power was more evenly distributed. Some service-users found this as part of a couple, others found it in other relationships with other service-users, and in some instances it could be found in relationships between staff and service-users, or between service-users and others in their lives who did not have a LD. This alternative positioning may lead to feelings of being valued, of being held in esteem and of



having pride in one's qualities. It might also enable one to feel effective in one's activities and relationships, and might counter feelings of loneliness and isolation that might otherwise ensue.

In my own interactions with service-users I was shown numerous photos, greeting cards and gifts that signified participants' status as 'valued others' in other people's lives, this was done with obvious pride. One service-user spoke of feeling "*honoured*" (SU3, 605), when his brother asked him to be best man at his wedding.

## **7 *Institutions, Power and Ideological Effects***

In this section I shall turn my attention to some Foucauldian concepts which appear particularly pertinent to the research that I undertook, specifically those that relate to sexuality and discipline. I shall consider how these concepts relate to issues of power, institution and ideology.

### **7.1 Sexuality**

In *History of Sexuality* (1978), Foucault traced changes in ideas about sexuality. Of particular relevance to the current study, he noted that in the eighteenth and nineteenth centuries the scrutiny of sexuality moved from rules and recommendations governing the sexual practice of a married couple, to a scrutiny of the sexuality of children and those ostracised from mainstream society, including those who today would be considered to have LD. In particular there were concerns about the lack of control that these latter individuals were assumed to have over their sexual instincts – their sexual behaviour was pathologised, recast as a symptom of their 'condition' and used as a means of constituting their identity. Such ideas legitimised the regulation of sexual behaviour, which was then controlled by the state, through the structure and organisation of institutional regimes.

In the current study concerns about service-users' sexuality were described by staff. For example one staff-member commented that a service-user would misunderstand

his relationships with women and assume that they were sexual when the staff-member in fact 'knew' that they were not. This caused the staff-member to intervene to ensure that his sexuality was kept under control and he did not try to take things 'too far'. Another staff-member talked about the 'inappropriateness' of service-users kissing passionately whilst in the centre, and of the need to set limits in this respect. In both these examples the staff were positioned as responsible, knowledgeable adults, and the service-users as naïve, and in need of guidance and control. This suggests that the institution of the centre served to regulate sexual expression. Further evidence that service-users might be restricted in their sexuality came from photographs that I was shown that were described as pictures of the participant on 'dates' with her partner. The photos showed the couple in various locations and were clearly taken at different points in time; however the couple always appeared to be accompanied by staff and/or a family member.

It is notable that the majority of service-users who I interviewed spoke of marriage, and this might be taken as an indication that times are changing for people who have LD and that the possibility of having a sexual relationship is becoming a real possibility. However, the dominance of romantic notions of intimate relationships might suggest that marriage is the *only* way in which a sexual relationship can be legitimised for the participants in this study. Marriage is a cultural practice through which a heterosexual relationship is validated and recognised in law and (often) religion. These institutions privilege a particular form of sexual coupling but undermine others. Marriage may offer a means through which a relationship is legitimised and taken seriously and so the discourse may have positive effects for service-users; however the dominance of this discourse raises questions about the extent to which alternatives are possible.

## **7.2 Power, discipline and the production of individuals**

In *Discipline and Punish: The Birth of the Prison* Foucault (1979) explored the relation of power to disciplinary institutions and practices, and how such power

exerts influence on the bodies of subjected beings (Danaher, Schirato and Webb, 2000). He traced changes in the penal system that led to modern reforms and an emphasis on rehabilitation through discipline, and regulation through surveillance. Foucault argued that the effect of these practices was to produce particular kinds of individuals.

The current study illuminated ways in which staff and service-users were coerced to act in particular ways, and become particular kinds of people through the operation of power, perhaps particularly surveillance. In the first instance there was the containment of service-users within the centre through the use of locked doors and the assignment of service-users to staff-members. Staff-members were called upon to supervise service-users whether they thought it necessary or not. Through acts of supervision, and their position as knowledgeable and responsible people, staff were able to make judgements about the skills and qualities that service-users possessed, and how these might be developed in order for the service-user to become 'productive' (or valued) individuals. Accordingly, service-users were 'trained' in order to develop and demonstrate particular skills and qualities – normative behaviours that are valued in society, whilst behaviours that did not conform to society's expectations were problematised and subject to responses designed to eradicate their occurrence. Tensions between 'choices' and non-normative behaviour were apparent in a number of staff accounts, for example: *"This lady...she likes to change her pants in the afternoon. It's a personal choice but the problem is that she keeps her pants in a sandwich box"* (SM2, 271-273).

Foucault also argued that the ultimate goal of disciplinary power was to produce self-regulating individuals – individuals who internalised the processes of surveillance and feedback and so appeared to choose to behave in socially valued ways, thus reducing the need for external controls. This too was apparent in the current study when a service-user talked about how she and her partner were planning to live together and how they were learning to do 'independent living' – which involved learning domestic skills: *"This place where we went last night... I*

*want to do that with him” (SU2, 184-185). Similarly a staff-member talked about service-users ‘choosing’ to engage in such activities: “Say somebody wants to live with their partner in the future, you’d say ‘Right, well what do you feel you need?’ and they’d probably need something like basic training in domestic skills, so that would be priority for them” (SM2, 17-20).*

Though the above quote suggests that service-users have increased opportunities to engage in activities that many people take for granted – in this case living with one’s partner – this is only achieved through submitting to do this in a particular way and moreover one which is not required of most people. It has been argued that current LD service provision represents a new dispersal of power relationships in the drive towards greater efficiency, rather than an emancipation or humanitarian reform (Drinkwater, 2005). Thus modern service provision serves to obscure the actual experience of relational power, by recasting coercion as ‘choice’.

## **8      *Concluding Comments***

In this analysis I have traced the ways in which particular constructions of relationships and discourses are utilised to achieve particular effects and legitimise particular practices, and that the implications that this might have for subjectivity. I have also considered the ways in which Foucauldian notions of sexuality and discipline were represented in the data. In the next chapter I will consider how these findings might be located within the literature, and what implications for practice these findings point to.



## CHAPTER 4: DISCUSSION

In this chapter I consider how the analysis of data presented previously might be positioned in relation to the literature on interpersonal relationships and people who have LD. Though much of this literature has been presented in the introductory chapter, some new literature is presented which appears particularly salient in light of the findings of the current study. I also consider how these findings might influence the reading of some other literature specifically that which relates to LD service provision, issues of identity for people who have LD and the phenomena of ‘infantilisation’. Following this I consider what implications for clinical practice this study might point to, before reviewing the strengths and limitations of my method, and potential future developments.

### *1 People who have Learning Disabilities and Interpersonal Relationships*

#### **1.1 Social Inclusion**

In the present study service-user participants talked about the interpersonal relationships that were important to them in their lives. The forms of relationships that were most commonly talked about were relationships with other service-users, relationships with family members and relationships with staff. Often when service-users described their relationships with others who did not have LD, they talked about those relationships being enacted in the public domain and involving the use of community facilities (for example going to the cinema or to the pub). It appeared to be the case however that the role of the person who did not have a LD in these instances was to facilitate service-users in accessing those resources, rather than engaging in the activity for mutual enjoyment and pleasure. Such relationships were indicated by descriptions of service-users being ‘taken’ to those places, and these descriptions were apparent in both staff and service-user accounts. It was also apparent from the photographs that I was shown by two service-users that although they were able to access community facilities with their partner – to go on dates for

example, that this was achieved with the approval and involvement of others (staff members or family members) who did not have LD. In an ethnographic study which explored how staff actions shaped the social identities of young people who had LD, Todd (2000) reported that staff often acted as ‘tour guides’ – facilitating individuals’ presence in a particular culture or community whilst at the same time insulating those same individuals from perceived threats such as negative social attitudes. These actions have parallels with the constructions of relationships as ‘doing for’, ‘guidance’ and ‘protection’ which were identified in the current study. In this study staff talked about their concern about the possibility of service-users encountering prejudice and discrimination in the community. These concerns legitimised actions aimed at ‘protecting’ service users from such experiences. Furthermore staff talked about how they tried to guide service-users with regard to ‘appropriate behaviour’ in the community. These constructions drew on discourses about people with learning disabilities that view them as being different to people who do not have learning disabilities, and of them being childlike by virtue of their dependence, naivety and vulnerability. The present study argues that the actions of staff in these activities can be located in their positioning as knowledgeable and responsible individuals; whilst those who have LD are correspondingly positioned as being naïve and dependent.

Often, research which has explored social inclusion has looked at the extent to which people with LD are able to engage in ‘ordinary’ activities, with ‘ordinary’ (i.e. non learning-disabled) people in their local community. This research however found that where participants described relationships based on mutuality, these relationships were usually with another person who was also a service-user. These relationships were meaningful and clearly of great value to the individual concerned. This research would suggest that moves to encourage relationships between people who have LD and those who do not *in favour* of relationships between people who have LD are undesirable on the following grounds: firstly such efforts may be bound to failure given the discourses about people with LD which currently prevail in our society; secondly where such relationships exist it is likely that the relationship will

be inequitable and that the person who has a LD may therefore be subject to oppressive treatment; and, thirdly that such ideas devalue the meaningful relationships that exist between people who have LD.

The current study concurs with previous research that suggests that where people with LD participate in community activities, they often do so in groups with other disabled peers and under the supervision of staff (e.g. Lord and Pedlar, 1991; Ralph and Usher, 1995; Ashman and Suttie, 1996). The current study however raises questions about the uncritical rejection of activities that people with LD engage in (with other people who also have LD) in segregated settings. Service-users expressed great enjoyment of some of the social activities they participated in at the centre and in other specialist services – specifically a social club for people who had LD. Their descriptions of these activities seemed to reinforce discourses of ‘difference’ and ‘infantilisation’ (they typically occurred under the supervision of staff, though of course this might not be so different to how community activities are ‘managed’). However it is perhaps wise to acknowledge what affirmative experiences might also be gained from such activities, and whether these same benefits might be conveyed by activities that take place in other settings. Perhaps activities of the former type offer comparatively more opportunities to engage in relationships where one feels secure, accepted and respected, and where shared experience is recognised. This is not to argue that there should be fewer opportunities for people with learning disabilities to access and enjoy community facilities that many people take for granted, but simply that there are different risks and rewards inherent in these different forms of activities, and that both may have a place. Indeed many group activities in other spheres of life take place between individuals who share something in common – experience, hopes and/or interests; the difference perhaps is that in other spheres people tend not to be defined exclusively by their participation in these groups.

## 1.2 Friendship

Previous research has indicated that people with LD have few opportunities to make and maintain relationships with friends (Krauss et al., 1992; Steering Committee for the Review of Commonwealth/State Service Provision and National Disability Administrators, 2000; Robertson et al., 2001; Emerson and McVilly, 2004). In the present study service-users who were interviewed about relationships that were important to them, made few references to friendships. One service-user told me that he did not really have any friends but that he desired such relationships. Staff interviewed as part of this research made reference to friendships between service-users, though these relationships were constructed as being superficial, perhaps because the idea of 'friendship' was treated as being synonymous with being 'friendly'. There was no indication that these relationships had any presence in service-users' lives outside of the day centre.

When friendships were described by service-users those relationships were exclusively with other people who had LD and who the individual knew through their use of services. Interestingly no individuals referred to staff members as being their friends, though a number of staff referred to their relationships with service-users as being friendships. Service-users' accounts of friendships highlighted the limiting impact of service structures on the ways in which the relationship could be enacted. For example one participant told me that she was not allowed to go into her friend's bedroom (they both lived in the same residential accommodation) as it was 'private', whilst another service-user commented that he no longer ate his evening meal with his friend as they had been moved into different units within the hostel. Knox and Hickson (2001) commented on similar barriers in their study. The present study argues that such practices may be legitimised by constructions of relationships which naturalise the idea that people who do not have LD (particularly staff-members) have authority over those who do.



Though much of the literature has problematised the experience of friendship for people who have LD, the studies by Knox and Hickson (2001) and Day and Harry (1999) emphasised the capabilities of their participants to engage in such relationships, and the resilience of those relationships in the face of the constraining influences wrought by service structures (in the former case) and familial attitudes (in the latter case). Similarly, the friendships described by service-users in the current study drew on constructions of relationships as ‘shared experience’, ‘emotional attachment’ and ‘empathy’ and endured despite the barriers they encountered.

There are a number of reasons why friendships may have received little attention by participants in this study. It may be that service-users had limited opportunities to develop friendships with others, as suggested by previous research; however there are alternative explanations. The subject matter of this research was very broad, participants were invited to talk about relationships and people who were important to them (or in the case of staff member interviews, participants’ own relationships with service-users, and their ideas about what relationships were like for service-users). Participants were not asked to comment specifically on particular types of relationships. Within the context of an (approximately) hour long research interview it would have been difficult to explore more than one or two relationships in great depth. The fact that participants (particularly service-users) chose to focus on other relationships (often romantic relationships) may reflect interests associated with the tasks of particular stages of life as has been suggested by Erikson (1982). Alternatively, the apparent absence might reflect that understanding of what constitutes a relationship is influenced by current and dominant discourse, and so relationships that do not conform to these expectations might be difficult to identify and explore.

### **1.3 Romantic Relationships**

In the present study a number of service-users spoke about romantic relationships. Such relationships were characterised by: a wish or intention to marry; doing things together; feelings of intimacy; and, an expectation of the permanence of the relationship. Participants' commonality with others and competence in engaging in valued social roles and traditions was emphasised in these accounts. These findings are comparable to those reported by Knox and Hickson (2001) and White and Barnitt (2000). No service-users reported that their relationship was a sexual one, though this might largely reflect the fact that I was a relatively unfamiliar person to them and that the service-users were mindful of cultural constraints which discourage talking about one's sexual relationships in such circumstances. Some service-users did talk about feelings of physical attraction towards their partners, though offered little elaboration of this. The fact that I was shown photographs by some service-users, of themselves and their partners apparently 'on a date' but accompanied by staff suggests that such relationships may be subject to a high-level of supervision and external control. Accounts of such relationships being enacted with approval and often direct involvement of family members, corroborates this claim which has also been reported in the literature (Löfgren-Mårtenson, 2004; White and Barnitt, 2000).

Interviews with staff members revealed ambivalent attitudes towards sexual relationships. One staff-member spoke of a service-user misunderstanding his relationships with females and mistaking a 'friendly' relationship for a 'sexual' one. The staff member spoke about this service-user's overwhelming desire for an intimate relationship and how this might place vulnerable service-users at risk. In doing so the staff member drew on discourses that locate people with LD as being qualitatively different to others, and positioned herself as somebody who was knowledgeable, responsible and in control. Correspondingly, the service-user was positioned as being naïve, dependent, potentially dangerous, and in need of control. This description offers support to the argument proposed by Cambridge and Mellan (2000), who argue that professional discourses pathologise the sexual behaviour of

men who have LD. Another staff-member spoke about how they and their colleagues felt uncomfortable and uncertain of their role regarding the physical aspects of a romantic relationship between service-users, whilst a further staff-member told me that they actively discouraged some physical exchanges between service-users (such as passionate kissing), but deemed others (holding hands and hugging) acceptable. These findings concur with those of Löfgren-Mårtenson (2004) and Aunos and Feldman (2002) who noted ambivalent feelings amongst staff-members and relatives with regard to sexuality and young people with LD. The present study however argues that such feelings may be driven by powerful historical and institutional discourse.

The absence of accounts of same-sex relationships both in the current study and in other literature that has utilised the first-hand accounts of people with learning disabilities is interesting. This may reflect the small numbers of participants in such studies, but it might also suggest that such relationships are devalued. Withers (1998) argues that both homosexuality and LD are often considered to represent 'degenerative' identities. He presents data from a study which explored how a group of men who had LD understood aspects of their identity (including sexual identity). He found that a number of the men (who had had extensive sexual contact with other men) seemed to hold such a degeneracy view of homosexuality and LD. Withers argued that clinicians need to confront the societal forces which cause these self-destructive beliefs.

#### **1.4 Parenting and Familial Relationships**

In the present study accounts of service-users as parents were conspicuous by their absence. Only one service-user expressed an expectation that they would become a parent at some point in their life, whilst one staff-member commented that the service-user he spoke about would probably have had the capability to parent but had lacked the opportunity having spent a great deal of his life in institutional care. No other participants mentioned parenthood. This may reflect an expectation that



service-users will not become parents, or a means of managing the knowledge that they never will – though I did not know whether any of the participants in the study had been sterilised, it is likely that some of the female service-users would have experienced menopause. Scior (2003) identified a dominant, romantic discourse of motherhood, followed by a discourse which identified motherhood as a source of emotional trauma. It was argued that this may have been a means of managing emotional dilemmas, for example that which arose for one participant through the knowledge that she would not be able to experience motherhood herself as she had been sterilised. It would appear that although marriage is a plausible possibility for some service-users, parenthood is not. The absence of descriptions of parenting in the present study is of concern. It suggests that although much of the rhetoric currently guiding service policy emphasises that people with LD should have the same choices, rights and opportunities as those enjoyed by people who do not have LD, this is failing to have an impact on actual practice. The fact that people who have LD continue to be regarded by many as dependent, naïve and lacking in responsibility offers some indication of what barriers may need to be addressed before this situation is likely to change.

With regard to familial relationships the current study found evidence that relationships between service-users and their own parents could be characterised by ‘childlike’ discourses which served to perpetuate constructions of relationships as ‘doing for’, and which legitimised practices of supervising, controlling and taking responsibility for service-users. As the study did not interview parents of service-users it is not possible to comment on whether these constructions were shared by parents or indeed whether such constructions and practice was driven by need to protect service-users from harm, as has been suggested by previous research abuse (McConkey and Smyth, 2003, Heywood and Huckle, 1995). Furthermore the current study suggests that much of the research that has been undertaken regarding relationships between parents and their adult children who have LD, is based on a construction of that relationships that emphasises dependency and the need to be ‘cared for’ on the part of the person with LD. This is an assumption that is perhaps



translated into the practice of services and marked by the frequent use of the term 'carer' in reference to the parents of service-users. This study demonstrated however that this is just one of a range of ways in which this relationship (and those with siblings) can be constructed. Participants in this study also spoke of familial relationships that were constructed as 'emotional attachment' and 'shared experience'. These constructions enabled service-users to be valued as a family member, and to share in experiences with others rather than be subjected to them.

### 1.5 Accepting Relationships

Although many of the accounts provided by staff in this study, pointed to their increased power relative to service-users and the ways in which particular practices reinforced discourses about people with LD being childlike and different, there were also some encouraging glimpses of other constructions of relationships that were possible. For example some staff spoke of having similar characteristics and/or interests to service-users, and of enjoying the company of service-users. Taylor and Bogdan (1989) offer a framework through which relationships which are based on mutuality between people who have LD and those who do not can be understood. They consider examples of 'accepting relationships' which they define as: *"A relationship between a person with a deviant attribute, in this case mental retardation, and a non disabled person, which is long-standing and characterised by closeness and affection and in which the deviant attribute or disability, does not have a stigmatizing or morally discrediting character in the eyes of the non-disabled person"*. They argue that such relationships are *"not based on a denial of the disability or difference, but rather on the absence of impugning the disabled person's moral character because of the disability"* (pp.27).

The authors describe data from a study that explored accepting relationships and argue that such relationships might be motivated by: a sense of family; religious commitment; humanitarian concern; and/or feelings of friendship. Where a sense of family significantly influenced an accepting relationship, feelings of commitment

and obligation to family members were often reported. In some instances it was reported that the family would not be the same family without any individual member, and many families viewed the member who had learning disabilities in terms of their positive characteristics and contribution to the family as a whole. Furthermore, a sense of family did not depend on biological relatedness as such relationships were also observed in foster and adoptive families. Accepting relationships did seem to occur most naturally, however, where the individual who had learning disabilities entered the family as a child rather than as an adult. This is particularly interesting in light of the present study where many staff argued about the importance of their relationship with a service-user being built up over a long period of time, and where comparisons to familial relationships were made. It perhaps suggests that an alternative interpretation might be made of the data presented here. In instances where religious commitment influenced an accepting relationship, the authors reported that this was based not merely on charity but on a commitment to people who have suffered or been wounded. The examples offered by the authors however relate to individuals who are Christians, therefore it is unclear how commitment to other religious convictions might influence the accepting relationships that Taylor and Bogdan describe. No references to religious beliefs were made by either staff or service-users in the current study.

Humanitarian concern as a motivation to accepting relationships was described by some participants in Taylor and Bogdan's study. In these instances sentiments ranged from a desire to do 'good work' to a desire to attack social injustice. The authors offer examples of relationships between staff and service-users where staff act beyond the requirements of their role, and in contrast to traditional definitions of professionalism that emphasise detachment. In this study many of the staff-members referred to the injustices and oppression that many service-users faced, and expressed a desire to advocate on their behalf and to work to achieve a better quality of life for service-users. Where feelings of friendship characterised an accepting relationship it was noted that relationships were described in terms of liking and enjoying one another's company, positive qualities, commonality, and a choice to be

together in the absence of obligation. Examples of such expressions were made on a number of occasions by staff who participated in this study.

Though the framework proposed by Taylor and Bogdan does not directly contradict some of the constructions and discourses identified in the present study, the existence of alternative frameworks for understanding relationships between people who have LD and those who do not, may undermine dominant discourses that perpetuate differences in power, and offer hope for change and the potential to challenge 'taken-for-granted' truths.

## **2      *The findings of this Study within the wider context***

### **2.1     Service Provision**

The white paper Valuing People (2001) remains the most influential document guiding current service provision for people with learning disabilities. It was based on ideas relating to 'normalisation' and 'social role valorisation' and set out the UK government's agenda for how people who have LD would be given opportunities to live full and independent lives as part of their local communities. The new vision for LD services was based upon the key principles of rights, independence, choice and inclusion. Though the implementation of the Valuing People agenda has led to many positive changes in the lives of people who have LD, its goals have been only partly recognised to date. In a report examining the progress made in achieving the Valuing People objectives (DOH, 2004), it was argued that the successes were due to the willingness of some people (who did not have LD) to make things happen, and that where little progress was made this reflected a lack of commitment to the agenda. The current study offers some exploration of dominant discourses about people with LD that remain powerful within society and which may at times constitute a barrier to achieving the goals of Valuing People.

The principle of inclusion has led to actions to include people who have LD in the activities of their communities. Day (2007) argues however that recognition is about

visibility, and that such visibility makes people potential targets. Moreover in the current social climate of increasing globalisation, consumerism and fragmented communities, there is a paradox in that there is a hope for 'fair' treatment within a society that is inherently unfair. The findings of this study would suggest that people who do not have LD, and who are positioned as being responsible for the safety and well-being of those who do; will be motivated to protect those people from the abuses and dangers in modern society. Correspondingly this comprises a threat to principles of inclusion, choice, independence and rights.

The discourses identified in the current study might also threaten those principles. It has been proposed that in adopting philosophies of normalisation, the implementation of the ideas proposed in Valuing People mainly places the responsibility for change in the hands of professionals and carers who do not have LD (Walmsley, 2001). The role of such people is to encourage people who have LD to achieve valued social identities. However it is the policy makers who get to define 'positive identity'. This was clearly evident in the current study as staff conscious of the expectations placed upon them, *guided* service-users towards specific outcomes. Such actions were grounded in discourses that viewed people with LD as being 'childlike' and 'different'. In these instances the authority that is invested in the position of 'staff-member' is apparent. Thus relationships of power within current service provision can militate against the aims of Valuing People. People who have LD can make choices only insofar that such choices are deemed 'valued' and culturally normative (and so do not constitute choices at all), and achieve 'independence' only when they have learned to govern their own behaviour to the standards demanded by society.

## **2.2 Identity**

In recent years the idea of an 'essential self' separate from social context, has been called into question. An alternative approach to identity argues that the experience of oneself is both context and relationship dependent. The present study emphasises



the role of interpersonal relationships in the management of identity; it is relevant therefore to consider what this might contribute to understandings about how people with LD view themselves.

The idea that 'learning disability' is a social construction is now well represented in the literature (e.g. Carlson, 2005; Race, 2002; Hatton, 1998), however it differs from other labels of category membership, in that it is unusual for a person to actively seek the label for themselves, the label is usually given by a professional in a position of power, and it often brings the person labelled into contact with specialist services (Gillman, Heyman & Swain, 2000). In addition the identity of being a person who has a LD might override other identities or category memberships that are meaningful to the individual such as gender (Burns, 2000), ethnicity, sexuality and religion (Walmsley and Downer, 1997).

Finlay and Lyons (2005) point to a number of studies which suggest that a significant number of people labelled as having a 'learning disability' (or equivalent label outside the UK) either "*refute the applicability of the label to themselves or do not use the label spontaneously to describe themselves or to explain the situations in which they find themselves*" (p. 120). It has been argued by some writers that denial may be a strategy which protects self-esteem (e.g. Edgerton, 1993; Sinason, 1992), and that parents, carers and/or others who hold positions of 'responsibility' might actively try to conceal an individual's awareness of their LD in order to protect them from the stigma that that identity conveys (Todd and Shearn, 1997). Such arguments resonate with medical and personal tragedy models of disability. The medical model of disability views disability as a fixed and immutable characteristic of a person, whilst a personal tragedy model emphasises the negativity of the label. These perspectives limit opportunities to develop and utilise alternative constructions of disability and identity. In the current study interviews with service-users often emphasised capability and competence in relationships, whilst staff-member interviews often emphasised service-users' dependency and the consequent need for staff to adopt a position of responsibility. This study suggests that ideas

about disability and limitation may resonate with service-users only in particular circumstances, for example when the actions of others restrict their autonomy.

Alternative constructions emerge when identity is considered from the perspective of a social model of disability (e.g. Goodley, 2000). From this position identity arises in local institutional practices, and interactions with particular groups of individuals and/or services. The idea that identity is an attribute which is fluid, dynamic and contextually driven is proposed by Rapley, Kiernan and Antaki (1998). In this study the authors refer to examples of people with LD talking about themselves and argue that the categorical membership as a person who has a 'learning disability' can be accepted or rejected according to the demands of the situation. They offer this as evidence of their participants' social competence and suggest that it reveals rather more about their commonality with 'ordinary folk' than their difference. Similarly, Finlay and Lyons (2005) outline the difficulties and contradictions that might be experienced by people who have learning disabilities, when considering the applicability of the label to themselves. Davies and Jenkins (1997) found that there was a conflict between people with learning disabilities' self-identity and categorical identity. They argue that although many participants did not directly articulate 'learning disability' as a personal attribute, this identity appeared to be promoted and internalised through experience and differential power relations. In the current study no service-users referred to themselves as having LD, though some talked about having physical disabilities. In their interactions with people who did not have LD (including myself) differences in power were apparent and these differences may have implications for identity. For example a number of service-users did not seem to expect opportunities to make choices and to be autonomous, did not resist when others acted on their behalf or instructed them, and at times did not take up opportunities that seemed to offer self-sufficiency. This suggests that in certain circumstances service-users may indeed experience their identity as one which is devalued and/or stigmatised. The study also however highlighted opportunities for more positive identities – in relationships based on mutuality, service-users could identify with others with whom they had a shared experience, could express and

evoke emotional attachment, and could experience physical attraction. These experiences also provided opportunities to take on valued roles as competent carers, romantic partners and/or collaborator in some shared task.

### **2.3 Infantilisation**

Within the current study a dominant discourse was identified which cast people with LD as ‘eternal children’. This discourse influenced constructions of relationships which emphasised service-users’ dependence, naivety, vulnerability and lack of control. This legitimised staff in acting on the behalf of service-users, of providing guidance and protection, and of imposing limits. Literature suggests that such discourses are also invoked against other groups of people who receive health-care services; the term ‘infantilisation’ is often used to describe these processes. This suggests that an exploration of constructions of relationships may also be relevant to other client groups.

One such group who may be subject to ‘infantilising’ experiences are people who have dementia. It may be relevant that dementia is traditionally conceived of as being a disorder involving neurological impairment which has an ‘organic’ basis – as is often also true of LD. Kitwood (1990) however proposed a new framework for understanding dementia – that of Malignant Social Psychology (MSP). MSP refers to the various processes through which people who have dementia are depersonalised. One such process is that of ‘infantilisation’ in which an individual is disempowered, having things *done for* them (much like the service-users in the present study), and receiving communications that they have the mentality and/or capability of a young child. In an earlier paper Kitwood (1988) proposed that dementia be reframed in terms of subjective experience, and in particular as the individual’s progressive loss of their ‘sense of self’. He argued that processes of MSP might actually serve to reinforce and attenuate this loss. Infantilising reactions from staff towards clients who had Alzheimer’s disease (AD) were also noted by Lyman (1990) who also argued that services that normalised rather than medicalised



the experience of AD provided the better model of care. Kitwood's model may however be relevant to older people even if they do not have a diagnosed dementia. For example Anderson, Ammarell, Bailey, Colon-Emeric, Corazzini et al. (2005) reported that analogies between caring for children and caring for elderly residents guided the behaviour of staff in nursing homes. In their study nurse assistants described residents as being vulnerable and in need for guidance, and explicitly compared this to tasks involved in caring for children. Infantilisation of older people has also been reported by Pesiah (1991). An explanation of these observations has been put forward by Nay (1998) who suggests that though nursing staff are *caring* this tends to take the form of 'care for' without recognition that participatory models of care ('care with') are also an option. In addition since many staff have no formal nursing education they may draw on mothering experiences to inform their practice.

Observations have also been made of infantilising comparisons and treatment directed towards people diagnosed as having a mental illness. Such observations have been made of people diagnosed with Schizophrenia (Corrigan, Baks Edwards, Green, Lickey Diwan & Penn, 2001; González-Torres, Orra, Arístegui, Fernández-Rivas & Guimon, 2007), whilst White (2003) offers a poignant account of how her experience of depression was compounded by the infantilisation and 'brutal routine' of the psychiatric milieu. The potential for such processes to wreak damaging effects was also highlighted in this account as for some time the misattribution of her 'symptoms' to her diagnosis of depression, masked the identification of a brain tumour.

Whilst the present study has highlighted ways in which the 'Eternal Child' discourse can contribute to the oppression of people who have LD; dominant discourses can also be invoked at times with positive effects. For example though discourses that infantilise an individual might work to limit their autonomy they might also enable the expression of emotions such as love and concern, and offer opportunities for the giving and receiving of care.



## 2.4 Emancipatory Approaches to research

There is a further area of literature to consider in relation to the current research. In this study people with learning disabilities were included as research participants, that is they were asked about their experiences, and their accounts of those experiences were considered to be valuable and credible. The role of service-users did not extend beyond this – I as a person who does not have a LD designed, implemented, analysed and reported on this research (with support from colleagues, who also do not have LD). I maintained a high degree of autonomy over the research: I chose the research topic and how it would be explored, and in doing so I set the boundaries of what could and couldn't be realised through this enterprise. It is paradoxical that in many ways this piece of work can be said to reproduce some of my own findings, in particular the construction of relationships as 'doing for'. This account 'speaks' on behalf of the service-users (and staff) that I interviewed. Opportunities for service-users to take a more active role in the research process, and to directly influence the development of 'new knowledges' about their experience were limited. Emancipatory approaches to research offer opportunities for empowerment.

Emancipatory approaches to LD research offer people who have LD the chance to become researchers themselves and to have a voice in the research community. It has been suggested that emancipatory research requires the following attributes (Zarb, 1992): that the research is a political action, that the research adopts the social model of disability and practically benefits disabled people, that disabled people have control of all aspects of the research from formulation of questions to dissemination, that disabled people are positioned as having expertise and are accountable to disabled people and their organisations, and that the subject matter explores and identifies appropriate avenues for change. Riddell, Wilkinson and Baron (1998) however point to the complexities of achieving this standard of emancipatory research criteria with people with LD as opposed to people who have physical disabilities. Walmsley (2001) develops Riddell *et al.*'s position and argues that although some LD researchers have been influenced by the disability

movement's arguments, there has been little debate about the practicalities and possibilities of using emancipatory approaches to research that involves people who have LD. She argues that within the literature it is very hard to find examples of emancipatory research in which people who have LD develop theoretical arguments of their own, and that careful thought must therefore be given to the position of researchers who do not have LD. In particular she notes the difficulties of non learning disabled researchers achieving a 'neutral' position given their increased power. Finally Walmsley considers the complexities of the issue of accessibility, and queries whether this is possible and whether concerns about accessibility have prevented inclusive researchers from articulating important but complex ideas.

There are however a small number of published papers which have used emancipatory approaches (e.g. Abbell, Ashmore, Beart, Brownley, & Butcher et al. 2007; Williams, 1999; Duckett and Fryer, 1998). In these examples the challenges of addressing the issues that Walmsley raises are apparent however there are promising indications that such approaches can lead to the redistribution of power in the research relationship.

### **3      *Implications for Practice***

In this study I have examined talk (and enactment) of relationships, from a critical realist perspective. Exploring relationships within this framework, enables the subject matter to be contextualised and understood as experiences involving the interaction of personal, interpersonal, historical and cultural factors. I shall now consider what implications for practice this research might have.

Service-users in this study demonstrated their ability to engage in a wide range of interpersonal relationships. These relationships were meaningful and of great significance to participants. In addition where relationships recognised the valuable contributions that service-users made to the lives of others, this seemed to have a positive impact on subjectivity. Services must recognise the value of these

relationships, work to reduce negative attitudes about relationships between service-users, and try to facilitate the maintenance of these relationships rather than generate obstacles to them.

The staff interviewed in this study were committed to making a positive difference to service-users' lives, however at times it seemed that the discourses about people with LD, that they had access to were limited and unsatisfactory. There may be a role for clinical psychologists in supporting staff to manage the conflict and uncomfortable feelings that this provokes, and in questioning taken-for-granted 'truths'. One way this might be done is through reflective groups which facilitate critical reflection upon the ideas that guides practice. This sort of work might help staff to resist the urge to work in particular ways (e.g. 'doing for' service-users) and manage the anxiety that this entails, or at least to be more conscious of the motivations for their actions and the impact that their work has on others. The value of such an approach was emphasised in the current study, where the effect of asking questions about staff-member's practice at times seemed to open up a reflexive space where the staff member could think about why they felt obliged to act in a particular way. Indeed a number of staff commented that they themselves were 'institutionalised' and another explicitly commented that much of the supervision that was done did not reflect the need for service-users to be supervised but the needs of staff to protect themselves from accusations of negligence should an adverse event occur. This points to the potential of facilitating a means for staff to come together to share such ideas, discuss points of difference and similarity and to formulate plans for collective action, where there is a desire to do things differently. David Campbell (2000) offers a useful model that might guide such work.

The study invites those working with people who have LD to critically reflect on their own practice, and how they construct their own relationships with people who have LD. This may lead to possibilities for new conversations in which relationships are negotiated and co-constructed between people. Whilst undertaking this research I found myself on a number of occasions unwittingly acting in, or

colluding with cultural practices that had limiting effects for service-users. Sinclair (2007) suggests the need for practitioners to deliberately evaluate their own participation in cultural practices in order to avoid perpetuating inequalities. This study supports that notion and suggests that it should be an on-going concern rather than a one-off event.

People who have LD need opportunities to engage in all kinds of relationships – intimate and non-intimate, traditional and non-traditional. Services should be aware of the ways in which they might privilege certain types of relationships (e.g. through Valentine Day celebrations), and think about ways in which they can acknowledge and legitimise other possibilities (for example by promoting and getting involved in ‘Pride’ campaigns).

#### **4 *Strengths, Limitations and Implications for Future Research***

In the following section I critically evaluate the research methodology. I consider the strengths and weaknesses of my approach and consider how this work might be developed through further research.

##### **4.1 Strengths**

- The study offered service-users the opportunity to tell their own stories about their lives and relationships. In doing so it demonstrated that people who have LD have important things to say about their lives, but that they need to be listened to both by services and researchers.
- The study utilised multiple data types, which helped to explore the topic from different perspectives and added depth to the analysis. The importance of collecting data in multiple ways when undertaking research with people who have LD has previously been emphasised in the literature (Mactavish, Mahon and Lutfiyaa, 2000).
- There are ethical and methodological problems which researchers encounter when they engage in research within one’s own field of practice or ‘practice-close research’ – in particular the difficulty of acknowledging and explicating



one's own preconceptions, and in the dualistic nature of the relationship between researcher and research participants (Lykkeslet and Gjengedal, 2007; Ceglowski, 2000). These tensions were apparent to me in the process of undertaking this research however I have striven to address this by acknowledging my interest and experience in working with this client group, in my attempts at transparency (both in the present account and in my interactions with participants at the time of undertaking the research), in my work at reflexivity and through my use of supervision. The reader of this account is perhaps best placed to judge how successful these efforts have been.

- Discussions about my interpretations of the data with colleagues provided a means of considering the credibility of my claims. Instances where these discussions led to a revision of my argument supports the notion that these discussions were informative and influential.
- My understanding of how relationships might be constructed and with what effects, evolved during the course of undertaking the research. It informed and was informed by encounters in my clinical practice. I anticipate that my views may continue to change as I reflect further on the research process, and as the further work that it entails enables me to present my thoughts and ideas to a new audience.
- Although I make no claims for generalisability, it is hoped that the presentation of: contextual description of the service setting and participants; explanation of the research process; and, the identification of dominant discourses that are closely linked to institutional power, might help the reader to consider the pertinence of these findings to their own work.

## **4.2 Limitations**

- One limitation of the current study is that in choosing to focus the research in one organisation, opportunities to explore other relevant service structures were closed down, for example literature suggests that where people who have LD live has important implications for their ability to form and maintain

relationships (e.g. Krauss and Erickson, 1988). It was felt that broadening the focus of the study would lead to a loss of rich contextual data; however this limitation could be addressed by further research.

- Participants interviewed as part of the current study generated a wealth of data about a range of different types of relationships. The current account has explored those that were most dominant, those that seemed most salient, and to a certain extent those that were noticeable by their absence. Further research is necessary to better understand specific forms of relationships that have received limited attention here (e.g. friendships).
- Given that one of the inclusion criteria for the current study was that service-users who attended the centre must be able to articulate something of their emotional experience; many individuals who attended the centre were unable to participate in the research interviews. More work perhaps needs to be done to identify creative ways of listening to the voices and experiences of those who are labelled as having 'severe' or 'profound' LD, and of undertaking research with this group of people.
- A large amount of data was collected in the process of undertaking this research, thus there has been a need to be selective in what is presented here. The reader has no means of examining the data that does not appear in this account, and are therefore limited in the extent to which they can consider what other interpretations and understandings might be applied to the material.
- Although I planned to select participants whose experiences reflected a diverse array of potential subject positions and resources, this was difficult to achieve in practice. For example many of the staff-members I interviewed held relatively senior positions within the staff hierarchy at the centre. This may reflect limitations of the sampling method and/or may suggest that less senior staff felt more anxiety about participating. In addition, all participants were 'white' and 'British' thus the potential of exploring differences in discourse arising from ethnicity and/or race was never realised.

### 4.3 Future Developments

The arguments presented here might be developed further through additional research:

- The current study has explored the different ways in which staff working with service users construct their relationship and with what effects; however it would be illuminating to explore how others, for example family members construct their relationship with their relative who has a LD.
- Literature suggests that some of the constructions identified here may not be unique to relationships that involve a person who has a LD, therefore an exploration of the ways in which relationships are constructed by and for, other marginalised groups, might also be illuminating.
- The primary data collection technique used here has both advantages and limitations. One of the limitations is that the interview encounter might be seem sterile compared with the rich nuances of actual lived experience. Ethnographic methods may get closer to this experience and provide additional insights into how relationships are constructed and with what effects in everyday life.
- The need to retain autonomy and control over the research process was in part influenced by the status of this account as an assessed component of a programme of academic study. This reproduced in the research relationship some of the inequality inherent in the relationships described by some participants. Further work might address ways in which research such as this can be conducted in a manner which allows for a redistribution of power in the research relationship.

## 5 *Conclusions*

In this study I have examined different ways in which service-users and those who work with them construct relationships. I have argued that particular constructions are disempowering and made meaningful by their reference to discourses which locate people who have LD as being 'childlike' and/or abnormal. These discourses are strongly linked to institutional power and their use may serve to reduce the

anxiety of staff who feel compelled to act in ways that demonstrate their responsibility and control; however they may also limit opportunities for autonomy for service-users who in turn may be left feeling helpless and frustrated. These findings helped to make sense of literature that suggests that people who have LD have impoverished interpersonal relationships, by arguing that this situation has developed and been maintained in a discursive context which devalues people who have LD. The study also identified more positive constructions which allowed for service-users and staff to engage in relationships that emphasised mutuality and in which power was more evenly dispersed. These relationships were valued and meaningful. Their existence has pointed to implications for practice and to challenges that must be addressed if the rhetoric of service philosophy is to become a reality.

## **6**     *Personal Reflections*

In undertaking this research I have been conscious of my desire to be balanced in my presentation of the findings. During the course of undertaking this project I was mindful of the way in which I was welcomed into the centre by both staff and service-users, and of the trust that was invested in me when participants voiced their views and experiences. In reporting some of the more critical findings of this research I have wrestled with feelings of guilt and disloyalty, and wondered whether participants might feel that they have been judged and/or blamed or felt that their trust in me was misplaced. I now feel that though the presentation of some of the findings might be uncomfortable (both for me and some of the participants), it is valuable in highlighting the power differential between service-users and those who work with them, and that the process has helped to identify positive ways of moving forward.

Undertaking this research has been challenging and uncomfortable at times. I am now more critical of my own practice; on a number of occasions, when working with people who have LD I have ‘caught’ myself drawing on the dominant



discourses critiqued here and felt frustrated and angry that despite my engagement with this research I too am fallible and often unable to circumvent their influence. On other occasions however I am more conscious of my power and position and able to use it to talk more openly about my relationship with clients; to question what others wish for the relationship to be and to think about how and whether these hopes can be achieved.

One of my hopes when I began my training in clinical psychology was that by the end of the course I would emerge as a fully-fledged confident clinician who could critically assess any given clinical scenario, know the ‘truth’ of it, and the actions to take to ‘fix’ it. This research has shaken these ideas. I question more and ‘know’ less. It feels awkward and unnerving at times – particularly when I am looked to for ‘answers’. I hope that I have the strength to hold this position when faced with pressure to be an ‘expert’ on the people that I work with.

## BIBLIOGRAPHY

Abbell, S., Ashmore, J., Beart, S., Brownley, P., Butcher, A., Clarke, Z., Combes, H., Francis, E., Hayes, S., Hemmingham, I., Hicks, K., Ibrahim, A., Kenyon, E., Lee, D., McClimens, A., Collins, M., Newton, J. & Wilson, D. (2007). Including everyone in research: The Burton Street Research Group. *British Journal Of Learning Disabilities*, 36, 1-4.

Anderson, R.A., Ammarell, N., Bailey, D., Colon-Emeric, C., Corazzini, K.N., Lille, M., Piven, L.M.S., Utley-Smith, Q. & McDaniel, R.R. (2005). Nurse assistant mental models, sense-making, care actions, and consequences for nursing home residents. *Qualitative Health Research*, 15, 1006-1021.

Ashman, A.F. & Suttie, J.N. (1996). The social and community involvement of older Australians with intellectual disabilities. *Journal of Intellectual Disability Research*, 40, 120-129.

Aunos, M. & Feldman, M.A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 285-296.

Bannister, P. (1994). Observation. In P. Bannister, E. Burman, I. Parker, M. Taylor & Tindall, C. (Eds.) *Qualitative Methods in Psychology: A research guide*. (pp.17-33). Open University Press: Buckingham.

Baum, S. (2006). The use of the systemic approach to adults with intellectual disabilities and their families: historical overview and current research. In S. Baum & H. Lyngaard (Eds.) *Intellectual disabilities: A systemic approach*. (pp. 21-41) London: Karnac.

Booth, T. & Booth, W. (1993). Parenting with learning difficulties: Lessons for practitioners. *British Journal of Social Work, 16*, 83-101.

Booth, T. & Booth, W. (2006) The uncelebrated parent: stories of mothers with learning difficulties caught in the child protection net. *British Journal of Learning Disabilities, 34*, 94-102.

Bramston, P., Chipeur, G. & Pretty, G. (2005). Conceptual principles of quality of life: an empirical exploration. *Journal of Intellectual Disability Research, 49*, 728–733.

Brandon, T. (2005). Empowerment, policy levels and service forums. *Journal of Intellectual Disabilities, 9*, 321-331.

Brown, H. (1994). ‘An ordinary sexual life?’: A review of the normalisation principle as it applies to the sexual options of people with learning disabilities. *Disability and Society, 9*, 123-144.

Brown, L., Branston, M. & Hamre-Nietupski, S. (1979). A strategy for developing chronological age-appropriate and functional curricular content for severely handicapped adolescents and young adults. *Journal of Special Education, 13*, 81-90.

Burns, J. (2000). Gender identity and women with learning difficulties: the third sex. *Clinical Psychology Forum, 137*, 137-139.

Butterworth, J. & Strauch, J.D. (1994). The relationship between social competence and success in the competitive work-place for persons with mental retardation. *Education and Training for Mental Retardation and Developmental Disabilities, 29*, 118-133.

Caine, A., Hatton, C. & Emerson, E. (1994). Service Provision. In E. Emerson, C. Hatton, J. Bromley & A. Caine (Eds.) *Clinical Psychology and People with Intellectual Disabilities*. (pp.54-76). John Wiley & Sons: Chichester.

Cambridge, P. & Mellan, B. (2000). Reconstructing the sexuality of men with learning disabilities: Empirical evidence and theoretical interpretations of need. *Disability & Society*, 15, 293-311.

Campbell, D. (2000). *The Socially Constructed Organisation*. London: Karnac Books.

Carlson, L. (2005) Docile bodies, docile minds: Foucauldian reflections on mental retardation. In S. Tremain (Ed.) *Foucault and the government of disability*. (pp.133-152). The University of Michigan Press: Michigan.

Ceglowski, D. (2000). Research as relationship. *Qualitative Inquiry*, 6, 88-103.

Chadsey, J. & Beyer, S. (2001). Social Relationships in the workplace. *Mental Retardation and Developmental Disabilities*, 7, 128-133.

Chappell, A.L. (1994). A question of friendship: community care and the relationships of people with learning difficulties. *Disability & Society*, 9, 419-434.

Corrigan, P.W., Backs Edwards, A., Green, A., Lickey Diwan, S. & Penn, D.L. (2001). Prejudice, social distance and familiarity with mental illness. *Schizophrenia Bulletin*, 27, 219-225.

Crapps, J. M. & Stoneman, Z. (1989). Friendship patterns and community integration of family care residents. *Research in Developmental Disabilities*, 10, 153-169.



Cummins, R.A. & Lau, A. (2003). Community integration or community exposure: a review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16, 145-157.

Cunningham, C.C. & Davis, J. (1985). *Working with parents: Frameworks for collaboration*. Milton Keynes: Open University Press.

Danaher, G., Schirato, T. & Webb, J. (2000). *Understanding Foucault*. London: Sage.

Danforth, S. (2000). What can the field of developmental disabilities learn from Michel Foucault? *Mental Retardation*, 38, 364-372.

Danforth, S. & Navarro, V. (1998). Speech acts: Sampling the social construction of mental retardation in everyday life. *Mental Retardation*, 36, 31-43.

Davies, C.A. & Jenkins, R. (1997). 'She has different fits to me': How people with learning disabilities see themselves. *Disability and Society*, 12, 95-109.

Day, S. (2007). A reflection on PostModernism and the transformation of failure in learning disability services within the independent public sector at the beginning of the 21<sup>st</sup> century. *British Journal of Learning Disabilities*, 35, 38-42.

Day, M. & Harry, B (1999). "Best friends": The construction of a teenage friendship. *Mental Retardation*, 37, 221-231.

Department of Health (2001). *Valuing people: a new strategy for learning disability for the 21<sup>st</sup> century*. London: The Stationary Office.

Department of Health (2001). *Seeking consent: working with people with learning disabilities*. London: The Stationary Office.

Department of Health (2004). *Valuing People: The Story so far*. London: The Stationary Office.

Dimitry, P. (2000). Dynamics of discourse: A case study illuminating power relations in mental retardation. *Mental Retardation*, 38, 354-362.

Dreyfus, H.L. & Rabinow, P. (1982). *Michel Foucault: Beyond structuralism and hermeneutics*. Brighton: Harvester.

Drinkwater, C. (2005). Supported living and the production of individuals. In S. Tremain (Ed.) *Foucault and the government of disability*. (pp.229-244). The University of Michigan Press: Michigan.

Duckett, P.S. & Fryer, D. (1998). Developing empowering research practices with people who have learning disabilities. *Journal of Community & Applied Social Psychology*, 8, 57-65.

Dudley, J.R. (2005). Best friends of people with mental illness and mental retardation. *Psychiatric Services*, 56, 610-611.

Duvdevany, I. & Arar, E. (2004). Leisure activities, friendships, and quality of life of persons with intellectual disability: foster homes vs community residential settings. *International Journal of Rehabilitation Research*, 27, 289-296.

Edgerton, R. (1993). *The Cloak of Competence: Stigma in the lives of the mentally retarded*. Berkeley: University of California Press.

Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for the publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

Emerson, E. & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in northern England. *Journal of Applied Research in Intellectual Disabilities, 17*, 191-197.

Erikson, E.H. (1982). *The Life Cycle Completed: A Review*. New York: W.W. Norton & Company.

Evans, G., Todd, S., Beyer, S., Felce, D. & Perry, J. (1994). Assessing the impact of the All Wales Mental Handicap Survey: A survey of four districts. *Journal of Intellectual Disability Research, 38*, 109-133.

Finlay, W.M.L. and Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment, 13*, 319-355.

Finlay, W.M.L. and Lyons, E. (2005). Rejecting the label: A social constructionist analysis. *Mental Retardation, 43*, 120-134.

Firth, H. & Rapley, M. (1990). *From acquaintance to friendship: issues for people with learning disabilities*. Kidderminster: BIMH Publications.

Fleming, I. & Stenfert-Kroese, B. (1990). Evaluation of a community care project for people with learning disabilities. *Journal of Mental Deficiency Research, 34*, 451-464.

Flynn, M.C. (1986). Adults who are mentally handicapped as consumers: issues and guidelines for interviewing. *Journal of Mental Deficiency Research, 30*, 379-387.

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M. & Beecham, J. (2002). The quality of life of people 12 years after resettlement from

long stay hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability & Society*, 17, 741-758.

Foucault, M. (1978). *History of Sexuality. Vol 1: An Introduction*. Translated by R. Hurley. New York: Pantheon

Foucault, M. (1979). *Discipline and punish: the birth of the prison*. New York: Vintage Books.

Gerson, K. (2002). Observation and interviewing: options and choices in qualitative research. In T. May (Ed.) *Qualitative Research in Action*. London: Sage.

Gillman, M., Heyman, B. & Swain, J. (2000). What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability & Society*, 15, 389-409.

González-Torres, M.A., Orra, R., Arístegui, M., Fernández-Rivas, A. & Guimon, G. (2007). Stigma and discrimination towards people with schizophrenia and their family members. *A qualitative study with focus groups. Social Psychiatry and Psychiatric Epidemiology*, 42, 14-23.

Goodley, D. (2000). *Self-advocacy and the lives of people with learning difficulties*. Buckingham: Open University Press.

Goodley, D. (2001). 'Learning Difficulties', the social model of disability and impairment: challenging epistemologies. *Disability & Society*, 16, 207-231.

Gordon, P.A, Tantillo, J.C., Feldman, D. and Perrone, K. (2004). Attitudes regarding interpersonal relationships with persons with mental illness and mental retardation. *Journal of Rehabilitation*, 70, 50-56.



Gough, B. & McFadden, M. (2001). *Critical social psychology: An introduction*. Hampshire: Palgrave.

Gregg, N. & Phillips, C. (1996). Adults with learning disabilities: empowering networks of inclusion, collaboration and self-acceptance. In N. Gregg & C. Hoy (Eds.) *Adults with learning disabilities: theoretical and practical perspectives* (pp.1-20). New York: Guilford Press.

Hatton, C. (1998). Intellectual disabilities – epidemiology and causes. In E. Emerson, C. Hatton, J. Bromley & A. Caine (Eds.) *Clinical Psychology and People with Intellectual Disabilities*. (pp.20-39). John Wiley & Sons: Chichester.

Heal, L.W. & Sigelman, C.K. (1995). Response biases in interviews of individuals with limited mental ability. *Journal of Intellectual Disability Research*, 39, 331-340.

Heslop, P. (2005). Good practice in befriending services for people with learning difficulties. *British Journal of Learning Disabilities*, 33, 27-33.

Heywood, B. & Huckle, S. (1995). Sexuality as a perceived hazard in the lives of adults with learning difficulties. *Disability & Society*, 10, 139-155.

Hinsby, K. & Baker, M. (2004). Patient and nurse accounts of violent incidents in a medium secure unit. *Journal of Psychiatric and Mental Health Nursing*, 11, 341-347.

HMSO. (2005). The Mental Capacity Act.

Horner-Johnson, W. & Drum, C.E. (2006). Prevalence of maltreatment of people with intellectual disabilities: A review of recently published research. *Mental Retardation and Developmental Disabilities*, 12, 57-69.

Johnson, K. (1998). Deinstitutionalisation: The management of rights. *Disability & Society, 13*, 375-387.

Kennedy, C.H. (2001). Social interaction interventions for youth with severe disabilities should emphasise interdependence. *Mental Retardation and Developmental Disabilities, 7*, 122-127.

Kitwood, T. (1988). The technical, the personal and the framing of dementia. *Social Behaviour, 3*, 161-179.

Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's Disease. *Aging and Society, 10*, 177-196.

Knox, M. & Hickson, F. (2001). The meanings of close friendships: the views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 14*, 276-291.

Krauss, M.W. & Erickson, M.E. (1988). Informal social support networks among aging mentally retarded persons: results from a pilot study. *Mental Retardation, 26*, 197-201.

Krauss M.W., Seltzer, M.M. & Goodman, S.J. (1992). Social support networks of adults with intellectual disabilities who live at home. *American Journal on Mental Retardation, 96*, 432-441.

Lessliers, J. (1999). A right to sexuality? *British Journal of Learning Disabilities, 27*, 137-140.

Le Touze, S. & Pahl, J. (1992). Facilitating friendships for people with learning disabilities. *Mental Handicap, 20*, 144-148.

Llewellyn, G. (1995). Relationships and social support: Views of parents with mental retardation/intellectual disability. *Mental Retardation*, 33, 349-363.

Löfgren-Mårtenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. *Sexuality and Disability*, 3, 197-207.

Lord, J. & Pedlar, A. (1991). Life in the community: Four years after the closure of an institution. *Mental Retardation*, 29, 213-221.

Lykkeslet, E. & Gjengedal, E. (2007). Methodological problems associated with practice close research. *Qualitative Health Research*, 17, 699-704.

Lyman, K.A. (1990). Staff stress and treatment of clients in Alzheimer's care: A comparison of medical and non-medical day care programs. *Journal of Aging Studies*, 4, 61-79.

Mactavish, J.B., Mahon, M.J. & Lutfiyya, Z.M. (2000). "I can speak for myself": Involving individuals with intellectual disabilities in research. *Mental Retardation*, 38, 216-227.

McCarthy, M. (1993). Sexual experiences of women with learning difficulties in long-stay hospitals. *Sexuality and Disability*, 11, 277-286.

McConkey, R. & Smyth, M. (2003). Parental perceptions of risks with older teenagers who have severe learning difficulties contrasted with the young people's views and experiences. *Children & Society*, 17, 18-31.

Moore, T. (2005). Friendship formation in adults with learning disabilities: peer-mediated approaches to social skills development. *British Journal of Learning Disabilities*, 33, 23-26.

Murray, J.L., MacDonald, R.A.R., Brown, G. & Levenson, V.L. (1999). Staff attitudes towards the sexuality of individuals with learning disabilities: A service-related study of organisational policies. *British Journal of Learning Disabilities*, 27, 141-145.

Nay, R. (1998). Contradictions between perceptions and practices of caring in long-term care of elderly people. *Journal of Clinical Nursing*, 7, 401-408.

Neugebauer, R. (1996). Mental handicap in medieval and early modern England: Criteria, measurement and care. In D. Wright & A. Digby (Eds.), *From Idiocy to Mental Deficiency*. London: Routledge.

Ohtake, Y. & Chadsey, J. (1999). Social disclosure among non-disabled co-workers in supported employment settings. *Mental Retardation*, 38, 25-35.

Parker, I. (1992). *Discourse dynamics: Critical analysis for social and individual psychology*. London: Routledge.

Parker, I. (2004). Criteria for qualitative research in psychology. *Qualitative Research in Psychology*, 1, 95-106.

Parker, I. & The Bolton Discourse Network. (1999). *Critical textwork: An introduction to varieties of discourse and analysis*. Buckingham: Open University Press.

Pearce, R. (1999). Advertising: critical analysis of images. In I. Parker and the Bolton Discourse Network. *Critical textwork: An introduction to varieties of discourse and analysis*. (pp.78-91) Buckingham: Open University Press.



Pearson, V., Wong, Y. & Pierini, J. (2002). The structure and content of social inclusion: voices of young adults with learning difficulties in Guangzhou. *Disability and Society, 17*, 365-382.

Pesiah, C. (1991). Caring for the institutionalised elderly: How easy is it? *Australian Journal of Public Health, 15*, 37-42.

Potter, J. & Hepburn, A. (2005). Qualitative interviews in psychology: problems and possibilities. *Qualitative Research in Psychology, 2*, 281-307.

Race, D.G. (2002). The historical context. In D.G. Race (Ed.) *Learning Disability – A social approach*. (pp.23-52.) London: Routledge.

Ralph, A. & Usher, E. (1995). Social interactions of persons with developmental disabilities living independently in the community. *Research in Developmental Disabilities, 16*, 149-163.

Rapley, M. (2003). *Quality of Life Research. A Critical Introduction*. London: Sage

Rapley, M. & Antaki, C. (1996). A conversation analysis of the ‘acquiescence’ of people with learning disabilities. *Journal of Community and Applied Social Psychology, 6*, 207-227.

Rapley, M., Kiernan, P. & Antaki, C. (1998). Invisible to themselves or negotiating identity? The interactional management of ‘being intellectually disabled’ *Disability & Society, 13*, 807-827.

Reinders, J. (2002). The good life for citizens with intellectual disabilities. *Journal of Intellectual Disability Research, 46*, 1-5.

Richardson A. & Ritchie, J. (1989). *Developing friendships: enabling people with learning difficulties to make and maintain friends*. Oxford: Policy Studies Institute.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Linehan, C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation*, 39, 201-214.

Riddell, S., Wilkinson, H. & Baron, S. (1998). From emancipatory research to focus groups: people with learning difficulties and the research process. In P. Clough & L. Barton (Eds.) *Articulating with difficulty: research voices in inclusive education*. London: Paul Chapman Publishing.

Roets, G. & Van Hove, G. (2003). The story of Belle, Minnie, Louise and the Sovjets: throwing light on the dark side of an institution. *Disability & Society*, 18, 599-624.

Schalock, R.L. (2005). Introduction and overview. *Journal of Intellectual Disability Research*, 49, 695-698.

Scior, K. (2003). Using discourse analysis to study the experiences of women with learning disabilities. *Disability & Society*, 18, 779-795.

Seale, J.K. & Pockney, R. (2002). The use of the Personal Home Page by adults with Down's syndrome as a tool for managing identity and friendship. *British Journal of Learning Disabilities*, 30, 142-148.

Seltzer, M.M. (1992). Family Care giving across the full life span. In L. Rowitz (Ed.) *Mental Retardation in the year 2000* (pp.85-99). London: Springer.

Sequeira, H. & Halstead, S. (2001). "Is it meant to hurt is it?" Management of violence in women with developmental disabilities. *Violence against women*, 7, 462-476.

Siegelman, C.K., Budd, E.C., Spanhel, C.L. & Schoenrock, C.J. (1981a). 'When in doubt say yes: acquiescence in interviews with mentally retarded persons. *Mental Retardation*, 19, 53-58.

Siegelman, C.K., Budd, E.C., Spanhel, C.L. & Schoenrock, C.J. (1981b). 'Asking questions of retarded persons: a comparison of yes-no and either-or formats'. *Applied Research in Mental Retardation*, 2, 347-357.

Sinason, V. (1992). *Mental handicap and the human condition*. London: Free Association Books.

Sinclair, S. L. (2007). Back in the mirrored room: the enduring relevance of discursive practice. *Journal of Family Therapy*, 29, 147-168.

Stansfield, A.J., Holland, A.J. & Clare, I.C.H. (2007). The sterilization of people with intellectual disabilities in England and Wales during the period 1988-1999. *Journal of Intellectual Disability Research*, 51, 569-579.

Steering Committee for the Review of Commonwealth/State Service Provision & National Disability Administrators (2000). *Consultancy Report – National Satisfaction Survey of Client of Disability Services*. Commonwealth of Australia, Canberra, ACT.

Szivos, S. (1992). The limits of integration. In H. Brown & H. Smith (Eds.) *Normalization the reader for the 90's* (pp. 112-133). London: Routledge.

Taylor, S. & Bogdan, R. (1989). On accepting relationships between people with mental retardation and non-disabled people: towards an understanding of acceptance. *Disability, Handicap & Society*, 4, 21-36.

Thompson, D. (1994). Sexual experience and sexual identity for men with learning disabilities who have sex with men. *Changes*, 12, 254-263.

Todd, S. (2000). Working in the public and private domains: staff management of community activities for and the identities of people with intellectual disability. *Journal of Intellectual Disability Research*, 44, 600-620.

Todd, S. & Shearn, J. (1996). Struggles with time: The careers of parents with adult sons and daughters with learning disabilities. *Disability & Society*, 1, 379-401.

Todd, S. & Shearn, J. (1997). Family dilemmas and secrets: parents' disclosure of information to their adult offspring with learning disabilities. *Disability & Society*, 12, 341-366.

Verdugo, M.A., Schalock, R.L., Keith, K.D. & Stancliffe, R.J. (2005). Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research*, 49, 707-717.

Vetere, A. (1993). Using family therapy services for people with learning disabilities. In J. Carpenter & A. Treacher (Eds.) *Using family therapy in the 1990s*. (pp. 111-130) Oxford: Blackwell.

Walmsley, J. (1993). Contradictions in caring: reciprocity and interdependence. *Disability, Handicap & Society*, 8, 129-141.

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 16, 187-205.



Walmsley, J. & Downer, J. (1997). Shouting the loudest: self-advocacy, power and diversity. In P. Ramcharan, G. Roberts, G. Grant, & J. Borland (Eds.) *Empowerment in everyday life: learning disability*. Jessica Kingsley Publishers Ltd.: London.

Weeks, J. (1989). *Sexuality*. London: Routledge

White, S. (2003). Mistaken Identity. *Psychiatric services*, 54, 479-481.

White, E. & Barnitt, R. (2000). Encouraged or discouraged? A study of people with learning disabilities and their experience of engaging in intimate relationships. *British Journal of Occupational Therapy*, 63, 270-276.

Williams, V. (1999). Researching Together. *British Journal of Learning Disabilities*, 27, 48-51.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: OU Press

Withers, P. (1998). When “clever” means “happy”: disability, desire and distress. *Clinical Psychology Forum*, 114, 10-11.

Wolfe, P. (1997). The influence of personal values on issues of sexuality and disability. *Sexuality and Disability*, 15, 69-90.

Wolfensberger, W. (1972). *The principle of normalization in human services*. Toronto: National Institute on Mental Retardation

Wolfensberger, W. (1983). Social Role Valorization: A proposed new term for the principle of normalization. *Mental Retardation*, 21, 234-239.

Wolfensberger, W. & Glenn, S. (1975). *Pass 3- Program Analysis of Service Systems: a method for the quantitative evaluation of human services*. Toronto: National Institute on Mental Retardation.

Wolfensberger, W. & Thomas, S. (1983). *PASSING (Program Analysis of Service Systems Implementation of Normalization Goals) Normalization and Criteria Ratings Manual*. Toronto: National Institute on Mental Retardation.

Zarb, G. (1992) 'On the road to Damascus: First steps towards changing the relations of research production'. *Disability, Handicap & Society*, 7, 125- 38.

## APPENDICES

- Appendix 1: Letter of ethical approval from Harrogate Local Research Ethics Committee
- Appendix 2: Project Poster (Please note that the poster is presented here on two separate pages, however in practice it was displayed on one A3 sheet.
- Appendix 3: Service-User and Staff-Member Interview Information Sheets
- Appendix 4: Service-User and Staff-Member Consent Forms
- Appendix 5: Transcriber Confidentiality Form
- Appendix 6: Literature Search Strategy

*Appendix 1: Letter of ethical approval from Harrogate Local Research Ethics Committee*



Research Ethics Administration Office  
50 Lancaster Park Road  
Harrogate  
HG2 75X

21 July 2006

Miss R D Wilson  
Psychologist in Clinical Training  
Academic Unit of Psychiatry and Behavioural Sciences  
School of Medicine  
University of Leeds  
15 Hyde Terrace  
Leeds LS29LT

Telephone: (01423) 554450  
Facsimile: (01423) 553392  
e-mail: Christine.Garrett@hdfh.nhs.uk

Dear Miss Wilson

**Full title of study:** People with learning disabilities and the construction of interpersonal relationships  
**REC reference number:** 06/Q1107/43

The Research Ethics Committee reviewed the above application at the meeting held on 18 July 2006. Thank you for attending with Dr Isherwood, Clinical Tutor, and discussing your study with the Committee.

**Ethical opinion**

The Committee asked you clarify your definition of relationships as your Protocol had suggested quite a range. You explained this question was quite open as some participants find it difficult to form close relationships and others would have formed friendships and/or sexual relationships. You were hoping to find a satisfactory symbol to convey this to participants.

You were asked whether referring to abusive or harmful relationships might encourage service users to exaggerate a situation in order to please you. You explained that these issues would be referred to in a general way as part of the consent and confidentiality process; you would not be asking a direct question about abuse. You confirmed satisfactory security arrangements for yourself whilst interviewing service users at [redacted] and you confirmed the security of data which would be locked away in your own name.

The Committee recommends that you review the wording of the staff information sheet. The Staff and Service User Information Sheets should include the sentence: this study has been reviewed by Harrogate Local Research Ethics Committee.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

**Ethical review of research sites**

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to complete Part C of the application form or to inform Local Research Ethics Committees (LRECs) about the research. The favourable opinion for the study applies to all sites involved in the research.

**HARROGATE LOCAL RESEARCH ETHICS COMMITTEE**

An advisory committee to North and East Yorkshire and Northern Lincolnshire Strategic Health Authority



*Appendix 2: Project Poster*

Project about Relationships and People with Learning Disabilities

I (Danielle) am doing a project at university.

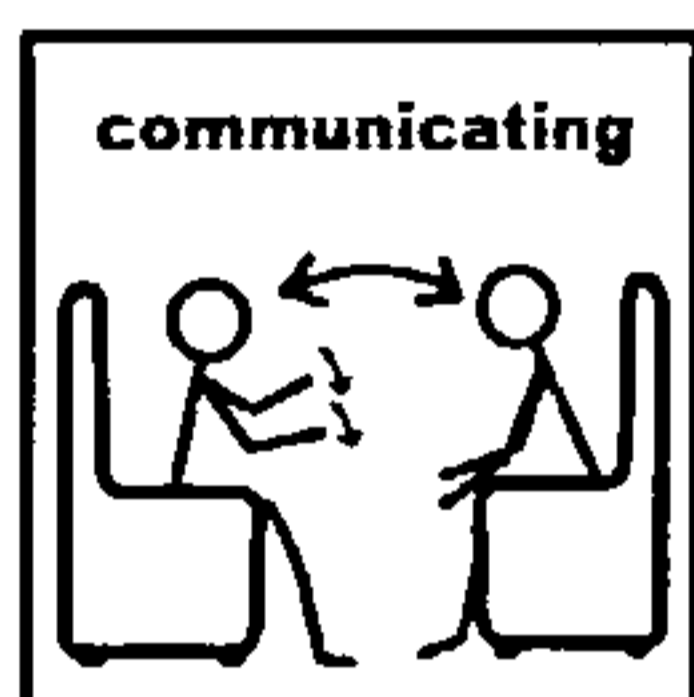
The project is about understanding how people who come along to the centre get on with the people they know.

It is also about understanding what other people (like staff) think about how people who come along to the centre get on with other people.

**What will it involve?**

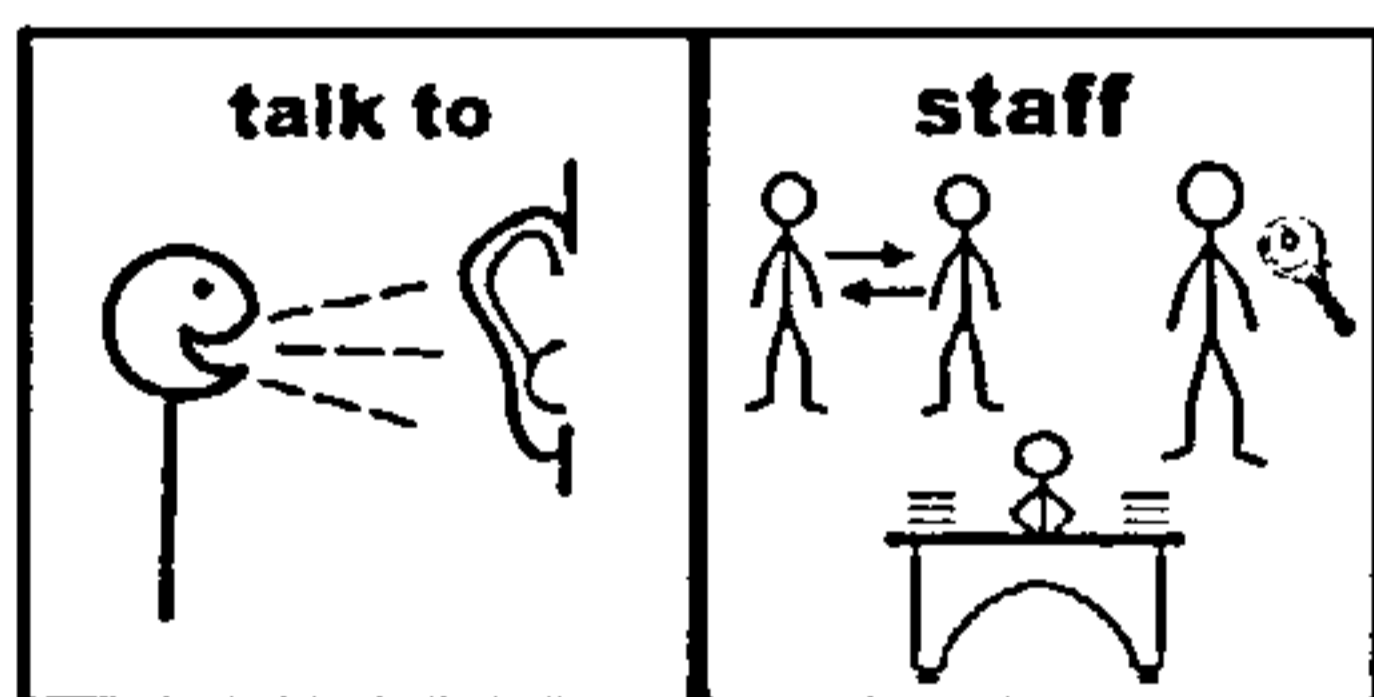
There are three parts to the project.

Part 1



I will be asking some of the people who come to the centre if they would like to talk to me about how they get on with other people.

Part 2



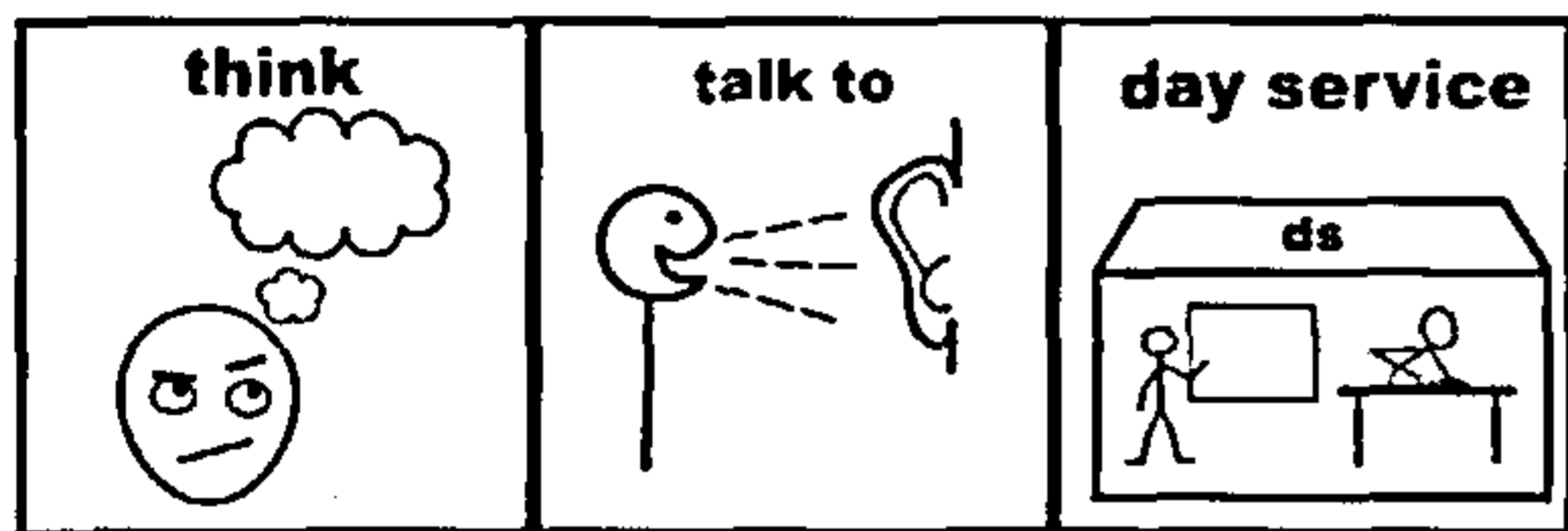
I will also talk to some of the staff to find out what they think about how people who come to the centre get on with other people.

Part 3



I will also watch some of the activities that happen at the centre to see how people get on with each other.

## What happens after that?



When the three parts of the project are done I will write about the things I have thought about. I will come and tell you and other people at the centre about this.

I will also write some things down that you and the staff here can look at.

## What is the point of the project?

The project might help us to think about what makes it harder for people who come to the centre to get on with other people, and what makes it easier.

## What to do if you want to find out more



If you have any questions about the research you are welcome to ask me. This is my address and phone number:

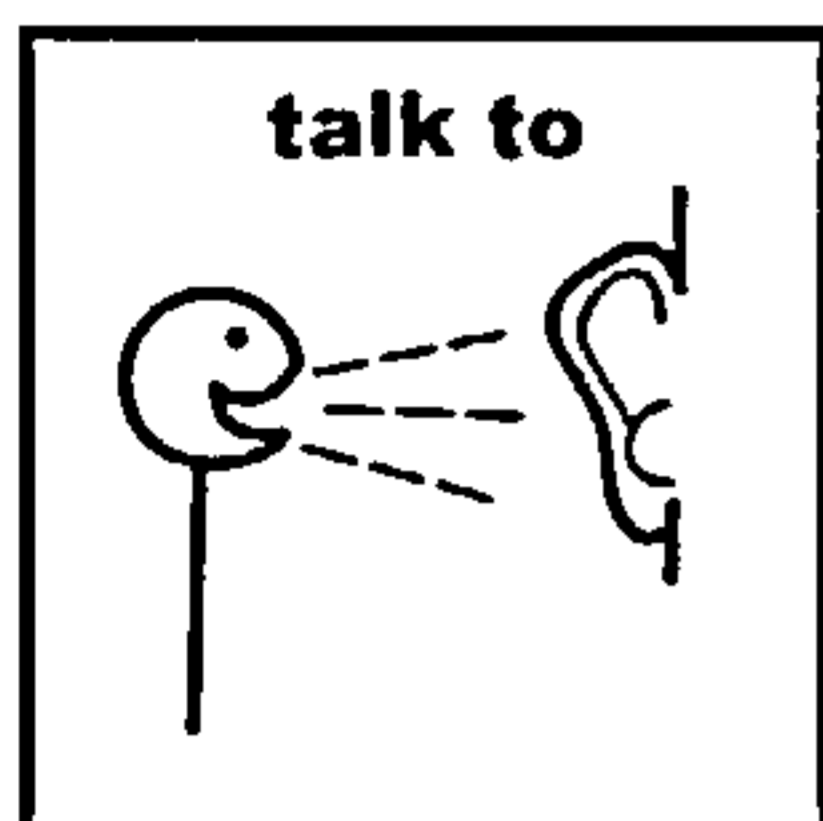
Danielle Wilson (Psychologist in Clinical Training)  
Clinical Psychology Training Programme  
The University of Leeds  
15 Hyde Terrace  
Leeds  
LS29LT



Telephone: 0113 343 2732

If it is difficult for you to contact me you can speak to one of the staff at the centre. They will ask me to come and see you so that you can talk to me about the research some more.

## Information Sheet for Service-User Interviews



I am asking you if you would like to talk to me about the people that you know and how you get on with them.

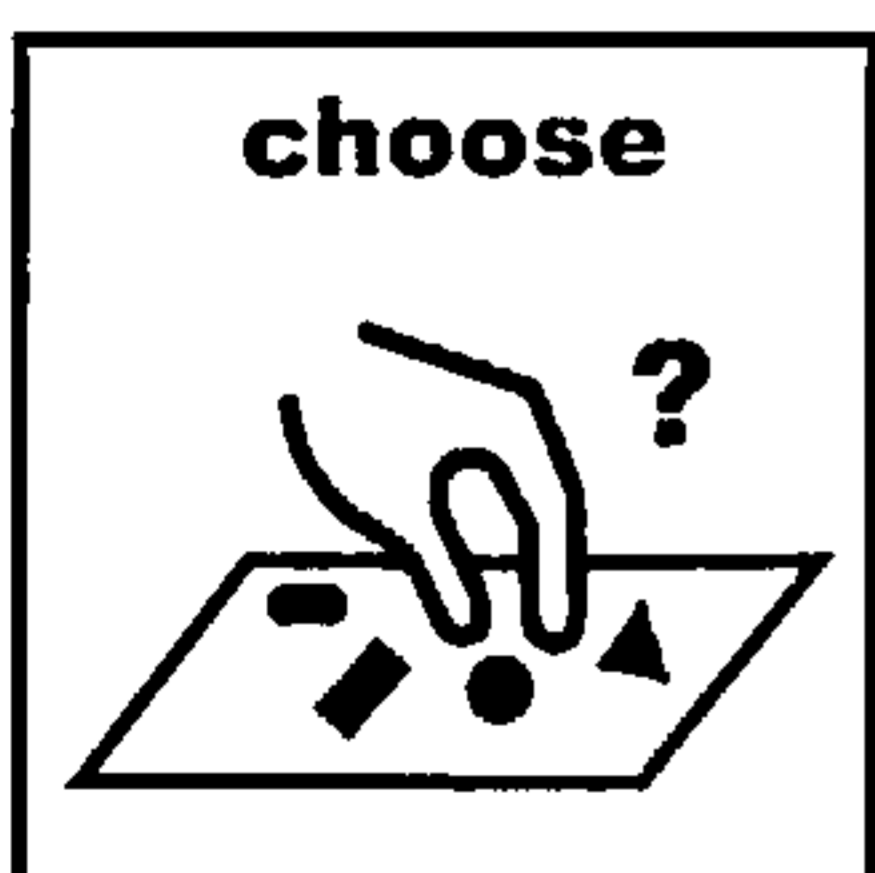
If you take part I would like to talk to you and ask you some questions.



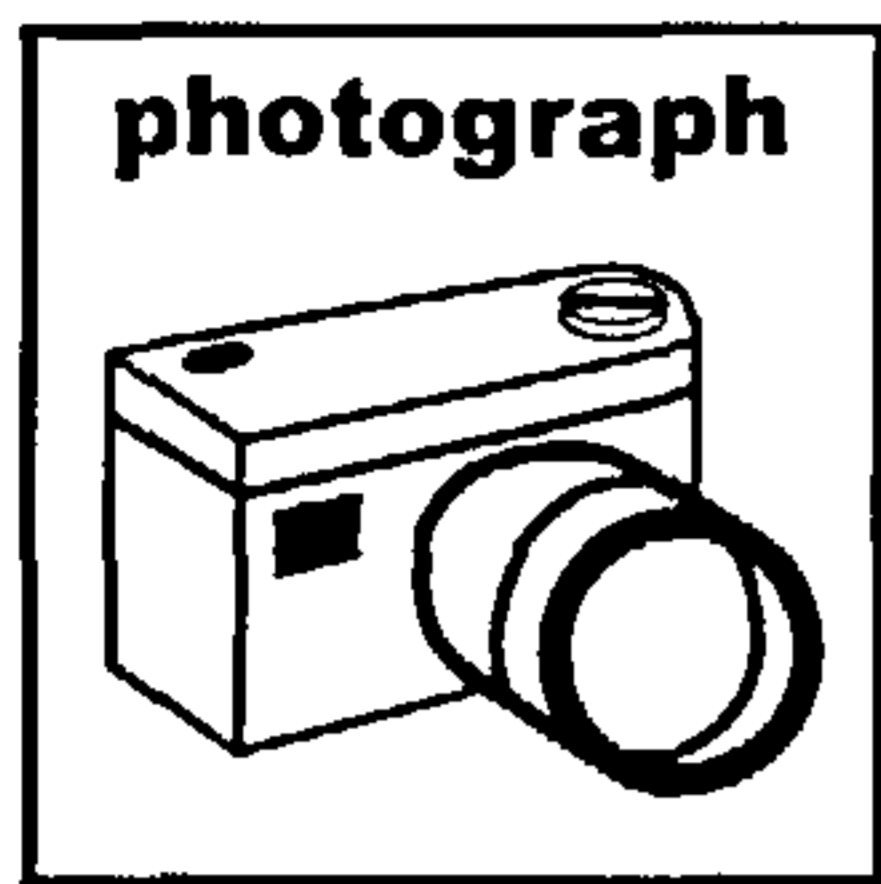
I will record this on tape and then write down what we said.

The questions that I ask will be about the people that you know and how you get on with them.

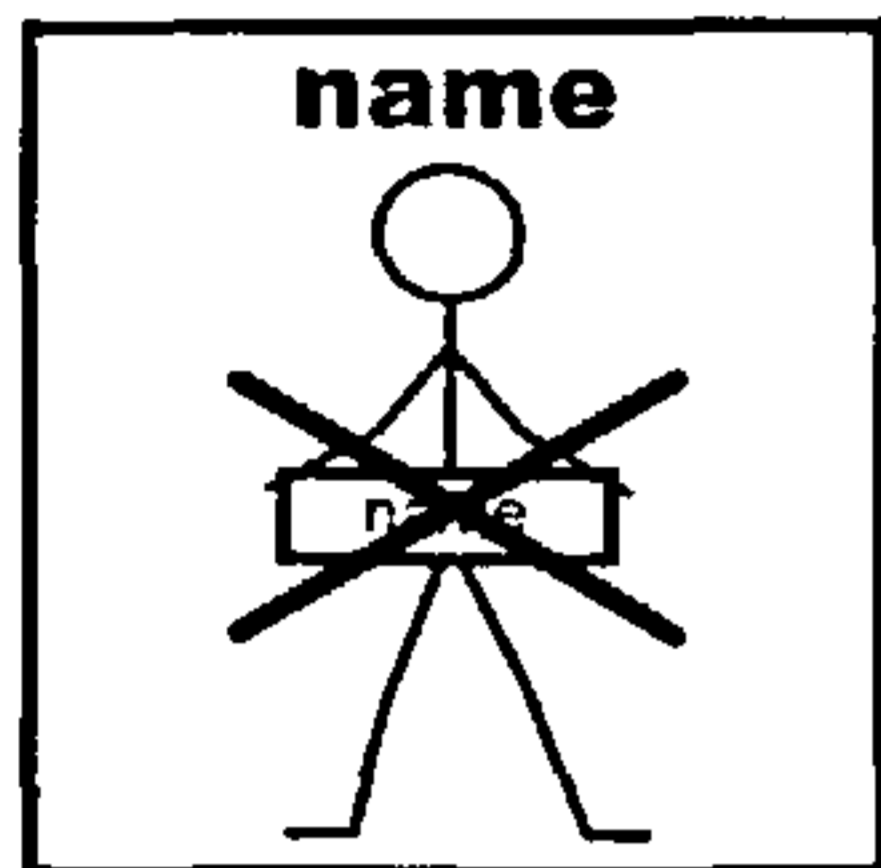
I will not ask any questions that I think might upset you.



You do not have to tell me anything that you don't want to and you can choose to stop talking to me at any time.



We might look at some photographs or some pictures to help us talk.



Your name will not be used in anything that I do for this research. I might use some things that you said when I write about the research but I will make sure that nobody is able to tell who said it.

The only time that I have to tell other people about what we talked about is if I hear about when you or someone else has been hurt. I will tell you if I have to do this.

**If you decide not to take part or want to leave the project**

If you don't want to take part it will not change any of things that you do at the centre.

If you do decide to take part you can change your mind at any time. If you do this I will not use any of the things we talked about when I write about the project.



## Information Sheet for Staff Interviews

I am asking you if you would like to talk to me about how you think people who come along to the centre get on with other people.

If you take part I would like to talk to you and ask you some questions.

I will record this on tape and then write down what we said.

The questions will be about your thoughts and experience of how people who come along to the centre get on with other people.

I might also ask about where you think some of your thoughts have come from.

I will not ask any questions that I think might upset you.

You do not have to tell me anything that you don't want to and you can choose to stop talking to me at any time.

Your name will not be used in anything that I do for this research. I might use some of the things you said when I write about the research but I will make sure that nobody is able to tell who said it.

The only time that I have to tell other people about what we talked about is if I hear about when you or someone else has been hurt. I will tell you if I have to do this.

If you decide not to take part or want to leave the project

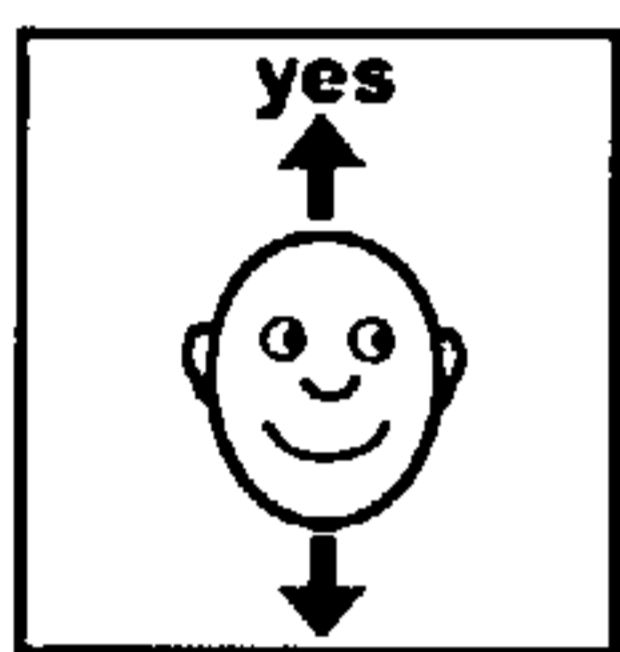
It is OK if you don't want to take part. It will not affect your job in any way.

If you do decide to take part you can change your mind at any time. If you do this I will not use any of the things we talked about when I write about the project.

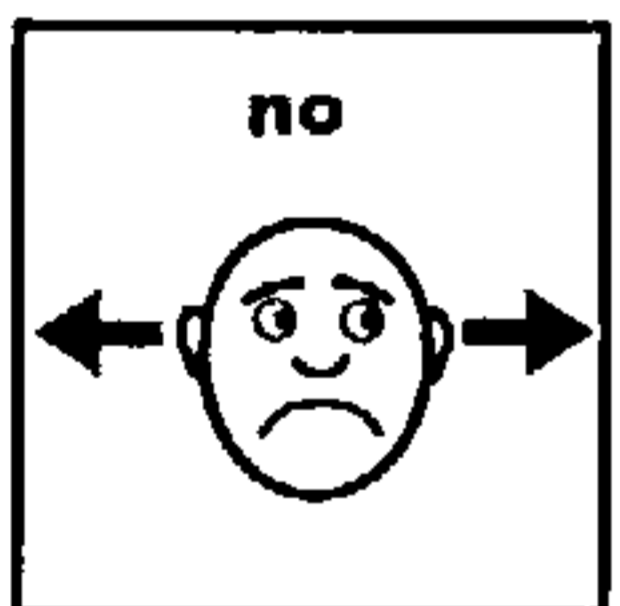
*Appendix 4: Service-User and Staff-Member Consent Forms*

**Service-User Participant Consent Form**

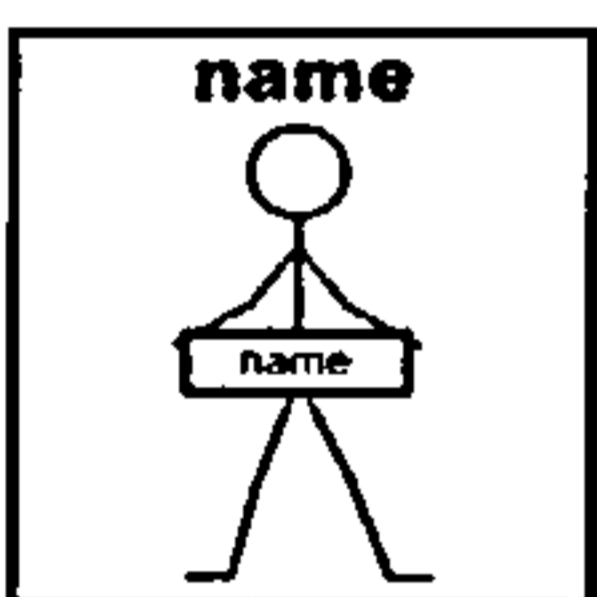
Researcher: Danielle Wilson (Psychologist in Clinical Training), Clinical Psychology Training Programme, University of Leeds, 15 Hyde Terrace, Leeds, LS29LT.



I agree to take part in this study.



I do not agree to take part in this study.



Name: \_\_\_\_\_



Date: \_\_\_\_\_

Signature: \_\_\_\_\_

## **Staff-Member Participant Consent Form**

Researcher: Danielle Wilson (Psychologist in Clinical Training), Clinical Psychology Training Programme, University of Leeds, 15 Hyde Terrace, Leeds, LS29LT.

**I agree to take part in this study.**

**I do not agree to take part in this study.**

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Signature: \_\_\_\_\_



***Appendix 5: Transcriber Confidentiality Form***

**Confidentiality Statement for Transcribers**

**Ethics Committee, School of Psychology, Leeds University**

The British Psychological Society has published a set of guidelines on ethical principles for conducting research. One of these principles concerns maintaining the confidentiality of information obtained from participants during an investigation.

As a transcriber you have access to material obtained from research participants. In concordance with the BPS ethical guidelines, the Ethics Committee of the D.Clin.Psychol course requires that you sign this Confidentiality Statement for every project in which you act as transcriber.

**General**

- 1) I understand that the material I am transcribing is confidential.
- 2) The material transcribed will be discussed with no-one.
- 3) The identity of research participants will not be divulged.

**Transcription procedure**

- 4) Transcription will be conducted in such a way that the confidentiality of the material is maintained.
- 5) I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access.
- 6) All materials relating to transcription will be returned to the researcher.

**Signed.....Date.....**

**Print name:**

**Researcher:** Danielle Wilson

## *Appendix 6: Interview Topic Guides*

### **Semi-Structured Interview Topics (Service-User)**

#### **1. Orientation**

(Reintroduce self, check out whether the person can remember what we talked about last time, refer to information sheet, check that person is still willing to proceed and that consent is valid).

#### **2. Context**

(Find out some information about the person – where they live, what sort of place is it, how long have they been there, who else lives there, where else have they lived etc. Also how long have they been coming to the centre, what sort of things do they do there, do they go to any other places during the week, have they attended any other places what were they like, etc).

- Before we start talking about the people that you know, can you tell me a little bit about yourself?

#### **3. Relationships that the person has/has had**

(What relationships do they have, what sorts of things do they do with them, what do people say about the relationship?).

- Mapping exercise to generate list of names:
  - Main or most important people who you know, or have known
  - Who is X?

- How long have you known X?
- Choose from list a person to talk about, then:
  - What usually happens when you're with X?
  - What do you usually do when you're with X?
  - Last time you saw X
  - A memory of X

**4. What are/were those relationships like?**

(What feelings does the person have when they're with that person, what is happening when they feel that way)

- How do you feel when you're with X?
- What keeps things going?
- What do you think will happen to you and X in the future?

**5. What gets in the way?**

(If there are things that the person would like to be different about their relationships what stops them from being the way they would like them to be?).

**6. Differences**

(Check out whether the person feels that their relationships are different to other peoples' – if so who are they different to and why do they think that things are different to them).

**7. Thanks**

**8. Debrief**

(Check out how the person has found the interview, what feelings did they have while we were talking and how do they feel now).

**9. What happens next**

(Explain how the research process will proceed, reiterate what happens with their information and how they will find out about what conclusions I've drawn from the research as a whole).



## **Staff Member Interview – Interview Schedule**

### **1. Context**

Find out some information about the person – how long have they worked in their current post and what sorts of things does their job entail. Have they worked in any other post that has involved people with learning disabilities, or had any contact with people who have learning disabilities in a non-occupational role? Work biography.

### **2. Service-User Related Questions**

Ask SM to choose a SU who they feel they know well enough to say a bit about their relationships. Ask why that particular SU stood out. Ask them to say a little bit about that SU. Ask them to choose a relationship that the SU has and to say a bit about the relationship (Note what sort of relationship it is). Aim to cover cognitive, affective, behavioural and social aspects of the relationship.

- What sorts of things do X and X do?
- Why do you think X and X get on?
- How do you think X feels when he/she is with X?
- What do people say about X and X's relationship?
- Does anybody that you know have a similar relationship to the sort of relationship that X and X have? What are the similarities? Are there any differences? What are they?

Ask for another type of relationship that X has and repeat as above.

Ask about the relationship that the SM has themselves with the SU:

- Can you tell me a bit about how you get on with X?
- What sorts of things do you do?
- Does your relationship with X have any similarities to any other relationships you have (outside of the centre)?
- Do you think that your relationship with X has any similarities with other relationships that X has (outside of the centre)?

### **3. Thanks**

### **4. Debrief**

Check out how the person has found the interview, what feelings did they have while we were talking and how do they feel now.

### **5. What happens next**

Explain how the research process will proceed, reiterate what happens with their information and how they will find out about what conclusions I've drawn from the research as a whole.

*Appendix 7: Interview Transcript Extract and Worked Example of Analysis*

*Transcript*

**Key:** SU2 – Service-User 2      R - Researcher

1      **R:**      I suppose I was wondering how he came to be your boyfriend? How  
2                      you got to know each other... that kind of thing.

3      **SU2:**    How I got to know him because... I mean he came here when he was  
4                      nineteen, in a way it's a long time twenty years.

5      **R:**      It is a long time. You're right.

6      **SU2:**    He's so lovely, he's so nice. He's my future. He's so lovely, so  
7                      sweet. He's so nice it's lovely. Now he's in the kitchen doing the  
8                      washing up.

9      **R:**      OK. You mentioned there about him being your future and I was  
10                     wondering apart from living independently which you're looking  
11                     forward to. What else do you think will happen in the future for you  
12                     and Michael?

13     **SU2:**    In a way. In the future er like my mum and dad you know talking  
14                     about respite? Because I want to give my mum and my dad a break  
15                     and that's our future... Independent living is like doing your own  
16                     cooking and washing and go shopping. Get out more. I want to do  
17                     that with him. Because he'll have to learn to do something to help  
18                     me. He wash up and I'll dry up... Can do that we can do meals.  
19                     Cooking we can do that. I know I do some here. Er when it's

20 Valentines Day like er doing all sorts. Valentine's Day and his  
21 birthday. And then sometimes I go to his house once a fortnight and  
22 he comes here five days a week and that's why. Er and I go on  
23 holiday. In future in this place where we went last night my mum  
24 and dad are pleased about it because I want to do that with Michael.  
25 Because he knows that I love him so much. And that's why he gave  
26 me that [shows researcher a key ring]. Because he went away with  
27 his family. He went to Disneyland.

28 **R:** And this was your present when he came back? It's lovely.

29 **SU2:** Yeah. Away with David and Colleen and Kelly and Gavin and Kate.  
30 I know I'm missing him there... Cause I had a phone call off him. I  
31 know I'm missing him. So they're away I got that and a toilet bag  
32 and nice t-shirts.

33 **R:** So you got lots of presents.

34 **SU2:** Yeah I have.

35 **R:** Oh that's lovely. I'll give you that one back [passes the key ring back  
36 to interviewee].

37 **SU2:** He goes all over with me. Not now because we went to er he went to  
38 what do you call that holiday now? Pontins... No not Pontins.  
39 Skegness. I went there with my mum and dad and me and Michael.  
40 We went there together er what else we went to? We do disco there  
41 riding them bikes. Doing that.



### *Worked Example*

In the following example I will concentrate on the how the stages of discourse analysis illuminate the ways in which the participant was able to construct her relationship with her parents and the impact that those constructions have for her.

### **Discursive Constructions**

In the above extract the service-user constructs her relationships with her parents in variety of ways. At line 14 the service-users talks about wanting to give her parents “*a break*”, and in doing so constructs a version of her relationship with them, in which she is a burden on them. The participant also talks about how her and her boyfriend went on holiday with her parents (lines 38-39). This could imply that the relationship involves doing things together and having shared experiences; however when trying to recall the name of the resort where they spent their holiday, she first draws on one which is primarily aimed at families who have young children. This suggests that her experience of holidaying with her parents was one in which she (and her boyfriend) are likened in some ways to young children, this further supports the idea that her relationship with her parents can be constructed as involving her dependency on them.

### **Discourses**

In the example cited the primary discourse which gives meaning to the text, is that of ‘The Eternal Child’. People who have learning disabilities are often talked about and related to as being ‘childlike’. In this discourse there is no expectation that the person will fully achieve the full independence which is typically associated with adulthood in western cultures. Thus it is assumed that the person will always be dependent on others to meet their needs. Those who provide that care are invested with responsibility and a duty to care and protect. The discourse is closely linked to ideas about ‘good parenting’ which are conveyed in cultural transactions (such as media transmissions and conversations between individuals), and in legal frameworks (such as ‘duty of care’ and ‘guardianship’).

### **Action Orientation**

In this example the participant is talking about her relationship with her parents alongside the relationship with her boyfriend. It is interesting to note that the constructions and discourses which she draws on to construct her relationship with her boyfriend emphasise her (and her boyfriend's) capability (lines 18-19) and responsibility (lines 17-18) which contrasts with the aspects of her identity that are emphasised in the relationship with her parents. Independence is an attribute which is highly valued in western culture and so drawing on 'The Eternal Child' discourse to characterise her relationship with her parents, might work to justify and defend her relationship with her boyfriend and their desire to live together, as being a 'better' way of being than that she is able to achieve in her relationship with her parents.

### **Positioning**

In this account positions of dependency and responsibility are emphasised. In the participant's relationship with her parents it would appear that she is the dependent whilst her parents are responsible carers; whilst in her relationship with her boyfriend they are both to some extent dependent on one another and have a responsibility to work together to ensure the continuation of their relationship and of them living together successfully. Interestingly, the participant's ambition of living with her partner offers the chance of emancipation from her dependent state – in living with her boyfriend she gives her parents the "*break*" (line 14) she feels they need.

### **Practice**

The positioning of the participant as a dependent and of her parents as being responsible carers, makes available particular forms of practice, and limits others. In particular this positioning affords those in the position of responsible carer the

authority to facilitate or constrain opportunities that arise in relation to the dependent person. In this extract we might interpret the participant's parents being "*pleased*" (line 24) about their daughter's anticipated move to live with her boyfriend, as their giving their approval and sanctioning this action. We might consider whether the participant would be able to pursue her ambition to live with her partner if this approval was withheld.

### **Subjectivity**

In this particular example the participant's subjective experience in (this particular version of) her relationship with her parents might include shame, as she feels that her need for care is tiring and a burden for her parents. This feeling state however might motivate her to seek alternative ways of constructing herself and her relationships with others, which is realised in her relationship with her boyfriend. She might also feel frustrated and angry however as it appears that her capability and capacity for autonomy can not find expression in her relationship with her parents. It is poignant to note that the ways in which she characterises the 'independent living' that she will be doing with her boyfriend, could also be applicable to her living with her parents.

Positive feelings too however might be evoked in this example. The participant is contemplating making a significant transition in her life and one which is likely to involve a degree of stress and uncertainty. Thus the participant might feel supported and contained by her parent's involvement at this time.

### **Institutions, Power and Ideological Effects**

In this example the participant refers to "*this place where we went last night*" (line 23). In an earlier section of the interview she describes 'this place' as a service where her and her boyfriend go to learn to do 'independent living' so that they will be able to live together in the future. She characterises 'independent living' as: "*doing your own cooking and washing and go shopping, get out more*" (lines 15-



16). In her reference to this service the participant indicates that her and her boyfriend's ability to live together is something that has to be learnt, demonstrated and approved of by powerful others, before it can become a reality. Since this a requirement that few other individuals are expected to engage with before they can pursue their preferred living arrangements, this highlights both the participant's reduced power and the continuing role of powerful institutions in her life.



## *Appendix 8: Extract of Observational Data and Worked Example of Analysis*

### **Description**

I can see six narrow windows. Cream coloured iron bars are visible and attached to the windows on the inside. I can also metal shutters attached externally to the windows, though these are rolled up right now. There are five large lights attached to the wall. They are switched off and encased in cages. The cages are rusty. There are two alarm boxes on the wall. There is graffiti on the wall. I can make out the words “Guy” and “Chris” and the words “Carter is a bum”, “Becca is fit” and Mirren n Vazza n Gem BMFL 2007”

### **Exploration of Connotation**

In this data two particular issues are suggested: a concern with security and devaluation. In the first case the bars on the windows, metal shutters, lights and alarms all imply that the building may be threatened. The physical devices described serve to protect the building, the activities that take place inside the building, and, those who inhabit it.

The graffiti on the wall may represent a physical attack on the building and henceforth a need for security; however it may also indicate a devaluation of the building and of those associated with it. Similarly, the rusting of the cages which encase the lights suggests that the building is poorly maintained, and therefore unimportant or forgotten.

### **Identification of Discourses**

The need for security implies vulnerability and a need for protection, thus this is closely linked to the ‘Eternal Child’ discourse which casts people who have learning disabilities as being in a state of perpetual dependency. The devaluation implied by

the graffiti and the poor maintenance of the building also suggests a devaluation of the primary purpose of the building, and of those who use it. This is associated with discourses that view people who have learning disabilities as being abnormal or 'less than human'.

### **Definition of Subjectification**

In this extract those individuals who are not associated with the building or its occupants are positioned as potential aggressors who must be guarded against. The effect of this positioning may be one of alienation and detachment and this may make the exclusion of those associated with the building more likely. Those people who have a responsibility for the structure of the building (which will include centre staff, local governmental organisation and national government) are positioned as protectors, whilst those who simply 'use' the building and its services are positioned as those in need of protection. In the former case the effect of this positioning may be the subjective experience of anxiety and obligation, which motivates the individual (or institution) to take actions which control and limit. In the latter case feelings of fear and powerlessness might be evoked, and those positioned in this way may look to others who are perceived as having authority and/or power to alleviate their distress and to help them feel safe.

The physical features of the building then can be seen to serve the purpose of 'othering' – distinguishing and differentiating between those who use the building and those who do not. The graffiti and poor maintenance of the building however have the effect of devaluing those who use the building, and this may serve to create the subject position of social outcast with commensurate feelings of shame and unworthiness. Those cast in such positions might then feel obliged to either retreat from the social community or alternatively might feel uncomfortable within it.

### **Search for Similar Discourses in Other Texts**

In the current study examples of both forms of discourse could be found in the interview data (see analysis), and also in other sections of the observational data (for example in the discourses identified in verbal exchanges). Furthermore, were the analysis to be extended these discourses might also be found in media representations of people who have LD, and in policies and legislation that relates to people who have LD.

### **Appreciation of Historical Dimension**

Discourses that construct people who have LD as being less than human can be traced back to the medieval period, during which LD (and mental illness) were demonised and attributed to supernatural causes. These ideas contributed to the exclusion of people with LD from society, as it was thought that only philosophers and priests could understand and/or intervene with such conditions. Ideas about learning disability underwent many transformations; however this devaluation has been evident in many of the re-conceptualisations. In Victorian England ideas about LD prevailed which equated it with low morality and a threat to society. This again served to alienate people with LD from their communities, and resulted in people with LD being excluded from society and cared for by ‘experts’ – namely health care professionals. The physical structures observed in the present study point to the endurance of barriers between people who have LD and those who do not, which results in alienation.

Discourses which view people with LD as being childlike are closely tied to ideas of innocence, vulnerability and a need to protect. These ideas too have a long history, whose influence is still very much in evidence today. Many of the models which guide current service provision are based implicitly on ideas of parenting, in which staff hold a position of ‘loco parentis’ or guardian in relation to the people that they work with. Ideas of ‘good parenting’ which are transferred through media, legal and religious frameworks make it difficult to resist the influence of this discourse.



### **Summary of Overall Structures of Meaning**

Constructions of dependence, protection and devaluation were identified in the observational text. These constructions implied that the people who used the centre required protection from the local community and that the people who used the centre were unimportant or unworthy. These constructions are made meaningful by discourses which locate people who have LD as being 'Eternal Children', and discourse which imply that they are 'less than human'. The impact of these discourses may be the subjective experiences of anxiety and obligation, and of shame and alienation. Furthermore these feeling states might be linked to particular actions (or inactions) such as vigilance, control, exclusion and passivity. Such discourses have a long history and are transmitted through cultural and social structures which make their influence difficult to resist.



### *Appendix 9: Literature Search Strategy*

MEDLINE (1966 onwards), PSYCHINFO (1896 onwards), and EMBASE (1980 onwards) were searched for relevant papers using the following strategies.

\$ indicates a truncation, e.g. disabilit\$ searched for all words with this root (such as disability, disabilities)

#### **Interpersonal relationships and People with LD**

interpersonal relationships OR relationships OR friendship OR sexuality OR parent\$ OR famil\$

**AND**

learning disabilit\$ OR mental retardation OR intellectual disabilit\$

**Limit results to English Language**

#### **Identity and People with LD**

Identity

**AND**

Learning disabilit\$ OR mental retardation OR intellectual disabilit\$

**Limit results to English Language**

Abstracts identified by these searches were reviewed for relevance and papers obtained. References of significant papers were also examined to identify additional papers not captured by the search strategy.