

# **Experience of Partner Selection and Relationships for People with Learning Disabilities**

Claire Bates

A thesis submitted in partial fulfilment of the requirements of  
London South Bank University for the degree of Doctor of  
Philosophy

August 2015

## **Acknowledgments**

My thanks go to the following people:

The eleven people with learning disabilities whose experiences and views were represented here. Without them allowing me access to their lives the research would not have taken place. Also all the staff at the two provider organisations for their support and input and allowing me to meet and speak to such amazing people.

My colleagues at Choice Support, especially Steven Rose and Sarah Maguire, who supported me to undertake the PhD, Kim Arnold for designing the easy-read literature for participants and Nancy Smallwood for her assistance with diagrams.

I also want to thank my excellent supervisory team which included Professor Keith Popple, Dr Louise Terry and Dr Mark Francis-Wright for the continual support and expert feedback over the years.

## Abstract

This original research presents first-hand accounts of intimate aspects of relationships for people with learning disabilities. Until relatively recently, people with learning disabilities have been prevented or strongly discouraged from engaging in relationships. The aim of the research was to understand what adults with learning disabilities look for in a partner and how these choices influence the relationships they experience. There has been minimal research which has explored the experiences of people with learning disabilities in relationships and no studies to date which have focused on partner selection for this group.

A hermeneutic phenomenological study, guided by the theory of Van Manen (1990), was conducted to directly explore participants' understandings of relationships. In-depth interviews were conducted with eleven participants and their interviews were transcribed to produce written narratives. Their narrative accounts and other information were utilised to develop participants' stories in order to enable readers to understand the experience of being a person with a learning disability in a relationship. The stories were analysed using an initial exploratory thematic analysis. A second hermeneutic phenomenological analysis was conducted on the interview transcripts to identify themes. The findings were examined in relation to attachment theory and Maslow's theory of motivation which attribute different levels of significance to love and relationships.

The analysis revealed that, for people with learning disabilities, love was a 'basic need'. Participants wanted a partner to love and to be loved by, someone who treated them kindly, who was affectionate and who provided companionship. Participants had to overcome significant barriers such as experiences of abuse and abandonment to develop relationships. Participants continued to experience other barriers such as a lack of autonomy due to the influence of staff, family or living environment, as well as limited social circles and a lack of life opportunities. The research identified that all participants had been able to overcome the barriers to the development of relationships. The facilitators to relationships included support from staff, positive role models within the family, physical affection and companionship. Maslow's hierarchy was revised to reflect the value of having a loving relationship with a committed partner to people with learning disabilities and to identify the support they required to facilitate and maintain this.

## Table of Contents

Acknowledgments.....	ii
Abstract .....	iii
<b>Chapter 1- Introduction .....</b>	<b>1</b>
1.1 Background to the Current Study .....	1
1.2 Terminology .....	2
<b>Chapter 2- Literature Review .....</b>	<b>8</b>
2.1 Conducting the Literature Review .....	8
2.2 Social, historical and cultural influences on relationships, sexuality and learning disability .....	11
2.3 Characteristics of Intimate Relationships .....	17
2.3.1 Maslow.....	18
2.3.2 What is Love? .....	22
2.3.3 Understandings of Intimacy.....	25
2.3.4 Partner Selection Research .....	27
2.3.5 Attachment.....	28
2.3.6 Maslow and Attachment Theory- Areas of Tension and Agreement.....	35
2.4 People with Learning Disabilities and Intimate Relationships .....	38
2.4.1 Historic Attitudes to People with Learning Disabilities .....	38
2.4.2 The Law.....	42
2.4.3 Professional Attitudes .....	43
2.4.4 Environmental Issues.....	46
2.4.5 Physical Relationships and Abuse .....	50
2.4.6 Experience of relationships beyond a sexual relationship .....	51
2.5 Research Questions .....	57
<b>Chapter 3- Epistemology, Methodology and Methods .....</b>	<b>59</b>
3.1 Introduction.....	59
3.2 Epistemological and Theoretical Understanding .....	60
3.3 Methodology and Phenomenological Perspectives .....	61
3.4 Interpretive Phenomenological Analysis - the discarded methodology .....	64
3.5 Hermeneutic Phenomenology - Max Van Manen .....	65
3.6 Research Design and Implementation .....	69
3.6.1 Inclusion Criteria .....	70
3.6.2 Sampling.....	71
3.6.3 Recruitment Method.....	72
3.6.4 Method - Interviews and Interview Guide .....	75
3.6.5 Research Interviews and Observation.....	78
3.6.6 The First Interview .....	82

3.7 Ethical Issues.....	83
3.7.1 <i>Intrusion of the Research</i> .....	83
3.7.2 <i>On-going Support</i> .....	84
3.7.3 <i>Confidentiality</i> .....	84
3.7.4 <i>Informed Consent</i> .....	86
3.7.5 <i>Reward</i> .....	88
3.8 My own process of hermeneutic phenomenological reflection.....	88
<b>Chapter 4 - Setting the Scene .....</b>	<b>93</b>
4.1 Introduction of the Participants and Participants Stories .....	93
4.2 Forming Attachments - Barriers and Facilitators to Relationships .....	97
4.2.1 <i>Attachment</i> .....	97
4.2.2 <i>Abandonment</i> .....	100
4.2.3 <i>Abuse</i> .....	104
4.2.4 <i>Protection and Autonomy in Relation to Abuse</i> .....	106
4.3 Participants' Stories in relation to Maslow's Theory.....	108
4.4 Summary of Exploratory Thematic Analysis .....	118
<b>Chapter 5- Need and Attachments: Forming the Relationships .....</b>	<b>121</b>
5.1 Theme One: Partner Selection.....	122
5.1.1 <i>Sub-theme One: Meeting potential partners</i> .....	122
5.1.2 <i>Sub-theme Two: Attraction</i> .....	124
5.1.3 <i>Sub-theme Three: Companionship</i> .....	128
5.2 Theme Two: Sexual and Physical Relationships.....	133
5.2.1 <i>Sub-theme One: Engagement in Sexual Acts</i> .....	133
5.2.2 <i>Sub-theme Two: Lack of Desire/Expectation for Children</i> .....	139
5.3 Theme Three: Influence of Staff/Group Living.....	143
5.3.1 <i>Sub-Theme One: Accommodation</i> .....	143
5.3.2 <i>Sub-theme Two: Restrictions placed on relationships by Housemates and Staff</i> .....	146
5.3.3 <i>Sub-theme Three - Staff Support</i> .....	151
5.4 Theme Four: Familial and Societal influences on Relationships.....	155
5.4.1 <i>Sub-theme One: Family Influence on Relationship Patterns</i> .....	155
5.4.2 <i>Sub-theme Two: Negative Familial Influence</i> .....	158
5.4.3 <i>Sub-theme Three - Societal Influence</i> .....	161
5.5 Summary of Hermeneutic Phenomenological Analysis .....	165
<b>Chapter 6- Recognising Needs and Rights: Key Developments in Policy, Practice and Attitudes.....</b>	<b>168</b>
6.1 Key developments affecting people with learning disabilities in the ninetieth, twentieth and twenty first centuries.....	168
6.2 Key developments' influence on the lives of participants.....	179
6.2.1 <i>1940 to 1959: Emergence of the Welfare State</i> .....	179

6.2.2 1960 to 1979: Protectionism, Paternalism and Progress .....	181
6.2.3 1980 to 1999 - Thatcherism, Care in the Community and Emerging Presence .....	184
6.2.4 2000 to 2009: 'New Labour', Investment in Public Services and Integration .....	187
6.2.5 2009 to 2013: Austerity, Global Recession, Spending Review, Cuts to Social Care and Winterbourne View .....	190
6.3 Summary of Key Developments in Policy, Practice and Attitudes .....	193
<b>Chapter 7- Discussion.....</b>	<b>195</b>
7.1 Introduction.....	195
7.2 What brings people together: Finding love as an adult with a learning disability..	196
7.2.1 Social Circle.....	196
7.2.2 Housing.....	199
7.2.3 Social Exclusion.....	201
7.3 Attracting and Attaching.....	205
7.3.1 Intelligence.....	205
7.3.2 Dependability.....	208
7.3.3 Physical Attractiveness .....	210
7.3.4 Sexual Relationships.....	212
7.4 Maintaining a relationships as an adult with a learning disability and the potential barriers.....	214
7.4.1 Staff .....	215
7.4.2 Service Providers.....	217
7.4.3 Having a learning disability.....	219
7.4.4 Neglectful Experiences and abuse.....	222
7.5 Chapter Summary.....	226
<b>Chapter 8- Conclusion.....</b>	<b>228</b>
8.1 Introduction.....	228
8.2 Revisiting the key findings and contributions to new knowledge .....	228
8.2.1 Theoretical Perspective.....	228
8.2.2 Empirical Perspective.....	232
8.3 Limitations of My Research and Implications for Future Research .....	236
8.3.1 Recruitment of participants.....	236
8.3.2 Diversity of the sample.....	237
8.3.3 Inclusion of staff.....	238
8.4 Recommendations for Policy and Practice .....	239
8.4.1 Basic Physiological Needs: Finding love .....	239
8.4.2 Safety and Security Needs: Safeguarding.....	240
8.4.3 Love and Belonging Needs: Physical Relationships.....	241
8.4.5 Self Esteem Needs: Autonomy and Socially Valued Roles.....	243
8.5 Dissemination .....	244
8.6 Concluding Reflections .....	245

<b>Reference List.....</b>	<b>246</b>
----------------------------	------------

<b>Appendices .....</b>	<b>284</b>
-------------------------	------------

Appendix 1 - What do people look for in a partner? Typology of Western Research .	285
Appendix 2 - Information sent to Gatekeepers .....	299
Appendix 3 - Change Picture Bank Cards – Shrunk Down- Actual Size A4.....	302
Appendix 4 - Interview Prompts .....	304
Appendix 5 - First Interview .....	307
Appendix 6 - Consent Form .....	314
Appendix 7 - Confidentiality (Easy Read).....	315
Appendix 8 - REC Email .....	317
Appendix 9 - Information about the research (Participants).....	319
Appendix 10 – Participants’ Stories.....	323
<i>Alan’s Story</i> .....	323
<i>Kerry and Dean’s Story</i> .....	323
<i>John and Caroline’s Story</i> .....	325
<i>Emma and Liam’s Story</i> .....	326
<i>Carrie and Joe’s Story</i> .....	327
<i>Mary’s Story</i> .....	329
<i>Peter’s Story</i> .....	329

## List of Tables

Table 1: Databases to conduct the literature search.....	8
Table 2: Attachment Theory and Maslow’s Theory of Human Motivation.....	37
Table 3: Essential Characteristics of an Exclusive Relationship .....	57
Table 4: IPA – Attractions and Reasons to Reject.....	65
Table 5: Types of Analysis Utilised .....	91
Table 6: Key Information about Participants .....	96
Table 7- Challenges faced by the Participants.....	113
Table 8: Main Themes Identified in the Participants Stories.....	114
Table 9: Timeline of Key Legislation/ Policy Changes/ Reports/ Landmarks.....	170

## List of Figures

Figure 1A: Maslow's Hierarchy of Needs .....	19
Figure 1B: Revised Hierarchy of Needs - Reflecting the challenges faced by people with learning disabilities as reflected in the literature .....	56
Figure 2: Data Collection .....	82
Figure 3: Revised Maslow's hierarchy: Forming intimate relationships as a person with a learning disability- what it means to them and the support required to achieve this. ....	231
Figure 4: Relational model of facilitators and barriers to relationships for people with learning disabilities .....	235



# Chapter 1- Introduction

This chapter will situate the importance of the research in terms of its contribution to academic knowledge and also why it was important to me as an individual and social care professional. It will identify the terminology used within the research, why this terminology was selected and, finally, broadly set out the research aims.

## 1.1 Background to the Current Study

I have worked within the field of learning disabilities for over twelve years within a large support provider organisation, in both operational roles such as a team manager and currently as a Quality Analyst, ensuring people get good support. I have also worked as a counsellor for people with learning disabilities as part of my master's degree in psychotherapeutic counselling. I wanted my research to contribute something meaningful to the lives of people with learning disabilities. Within my own life, I value the relationship I share with my husband. However, my experiences have shown that, compared to the wider population, fewer people with learning disabilities within the organisation in which I worked had this type of relationship with a spouse or long-term partner. It may have been that this organisation was atypical within the field of learning disabilities, but this was unlikely. The organisation supports approximately 1000 people nationally, which suggests a good cross-section of the UK population of adults with learning disabilities. This led me to consider intimate relationships as a research topic and how much is known about this aspect of life for people with a learning disability.

Emerson and Hatton (2008) estimated that 985,000 people in England have a learning disability. Emerson *et al.* (2005) *National Survey of People with Learning Disabilities* found that only 4% of the 2,898 participants interviewed had a partner. Due to my experiences I view being in a relationship positively but I am aware this is biased. There are, however, numerous studies which demonstrate the benefits of being married or being in a long-term relationship, which include economic benefits (Chun and Lee, 2001), increased mental wellbeing (Blanchflower and Oswald, 2004) and better physical health (Waite, 1995).

Prior to the large scale NHS hospital closures in the late 1980s and 1990s, a high number of people with learning disabilities were confined to institutions isolated from mainstream society and segregated by sex (Brown, 1994). This limited peoples' opportunity to engage in romantic relationships with members of the opposite sex.

There was a fear in society regarding procreation for people with learning disabilities. There was a concern that this would lead to an increase in the number of children with disabilities, affecting the quality of the general population (Barker, 1983). Relationships for this group historically were discouraged. However, the world of social care has experienced significant changes since the 1980s: people are now more likely to live with families, in smaller residential services or alone and have more opportunities to engage in mainstream society. Article eight of the Human Rights Act (1998) states that all individuals have the right to a 'private and family life', however, despite the advances in social care provision, few people with a learning disability have a partner or are married. It is unclear if this is due to external factors such as restrictions from staff/family, lack of social opportunities to meet a partner or internal factors such as poor interpersonal skills that halt the development of relationships. The review of the research literature identified few studies which explored the relationships of people with learning disabilities. Typically, research which explored relationships for people with learning disabilities focused on abuse, sexual relationships or sexual education. The review of the literature did not yield any information on specifically what people with learning disabilities looked for in a potential partner.

## 1.2 Terminology

This Section establishes the terminology and criteria applied within my research to define participants and their relationships.

### Definition of Learning Disability

The participants who took part in the research were all adults with a learning disability. The term 'learning disability' is a recognised term used by the Department of Health within their policy and practice documents.

In *Valuing People* (2001), 'learning disability' was defined as a:

- Significantly reduced ability to understand new or complex information, to learn new skills
- Reduced ability to cope independently
- An impairment which starts before adulthood with lasting effects on development.

(Department Of Health, 2001, p.14)

This can affect individuals in many ways, such as

- Their ability to communicate, organisational skills and remember accurately

- To manage risk and safety
- To undertake day-to-day tasks such as cooking, managing money or keeping a home

The definition of learning disability above (Department of Health, 2001) highlights the reality of the physical and cognitive impairments experienced by people with learning disabilities. Additional impairments associated with having a learning disability can include higher rates of epilepsy (Chapman *et al.*, 2011), increased prevalence of mental health issues (Cooper *et al.*, 2007) and an increased rate of behavioural problems which challenge service providers (Koritsas and Iacono, 2012).

Learning disabilities exist on a continuum and an assessment of intellectual and adaptive function is conducted to determine where people fall upon this (Murray and McKenzie, 2014). Individuals can be classified as having a profound, severe, moderate or mild impairment. Learning disability is partly assessed by use of 'Intelligence Quotient' (IQ), a psychometric test used to assess intelligence. The average IQ within the UK is approximately 100: IQ's over 70 are considered normal and a person with an IQ under 70 is considered to have a learning disability (Department for Work and Pensions, 2008). Adaptive functioning is assessed using the Vineland Adaptive Behaviour Scale (Sparrow *et al.*, 1984), where a person must present a deficit in two or more areas to be diagnosed with a learning disability. Areas include: 'communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety' (British Psychological Society, 2000, p.6). The level of support a person requires to function in their daily life determines their place on the disability continuum. For example, people with profound learning disabilities would require full support in all areas of their life whereas people with mild learning disability would require only minimal support. People with profound and severe learning disabilities display no/ minimal verbal communication and higher rates of mobility/sensory impairments compared to individuals classified as having moderate/ mild learning disabilities (British Psychological Society, 2000).

The nature of disability within the UK has been understood predominantly through two contrasting models: the medical and the social model. The medical model of disability was outlined in '*International Classification of Impairments, Disabilities and Handicaps*' (World Health Organisation, 1980) and has been influential in the treatment of people with learning disabilities. This model focuses on a person's physical or cognitive deficits (Parchomiuk, 2012), classifying them by medical condition, disability or impairment

(Stalker *et al.*, 1999). The medical model is paternalistic and does not recognise individuals' ability to increase independence. The 'Fundamental Principles of Disability' which developed the 'social model of disability' was published in 1975 by the Union of Physically Impaired Against Segregation' (UPIAS). The social model of disability gained recognition in the 1980s, its key aspect being the separation of the impairment (the loss/ limitation in functioning) from the disability (UPIAS, 1975). Disability was defined as 'the meaning society attaches to the presence of impairment' (Chappell and Lawthom, 2001, p.46). The model claims society disables individuals through discrimination and not providing adequate adaptations or support. This locates the problem of disability within society rather than arising from the individual's impairment (Chappell and Lawthom, 2001). The social model of disability gained prominence and acceptability throughout the 1980s/1990s. It was influential in reducing prejudice, increasing civil rights and promoting inclusion for disabled people (Owens, 2015).

In the past decade, the social model has been criticised for not recognising that a learning disability is more than a social construct by failing to acknowledge the 'embodied experience of disability' (Owens, 2015, p.389). For individuals with a learning disability, there is an embodied reality of their impairment which must be accepted. The social model fails to appreciate the associated cognitive deficits which are an embodied reality for some people with learning disabilities. Such deficits include: poor decision making ability (Smyth and Bell, 2006 and Schelly, 2008); an inability to think abstractly (Schelly, 2008), and difficulties surrounding social interaction (Mansell, 2010). Fyson (2009) argued that post *Valuing People* (DoH, 2001), services for people with learning disabilities have afforded considerable significance to choice and independence. However, for many people with learning disabilities independence and autonomy are not possible, due to the embodied reality of their disability. 'If these people were able to be fully independent and to make important life choices without support then they would not be receiving state-funded services in the first place (Fyson and Kitson, 2007, p.434). For people with learning disabilities, this is their lived experience.

Descartes' dualism conceptualises a separation between body and mind (Hart, 1996) which resonates with the medical model of disability which conceptualises bodies and minds as either 'normal' or 'abnormal', alternatively, the person is either 'able' or 'unable'. Learning disabilities are often caused by, and can present as, a collection of concrete medical indicators (e.g. Patau syndrome and Down's syndrome) and symptoms which then, depending on the level of their impact, affect people's ability to look after their own welfare and advance their own standing within society. The social

model recognises an obligation to address the barriers within society which pose difficulties for people with disabilities and to provide support systems but ultimately, both the medical and social model position the person with a learning disability as 'other' and therefore separate. This social model lacks the understanding of the social constructionist interpretation of disablement which 'argues for the inclusion of embodied experiences in disability accounts' (Owens, 2014, p.289). The social model is rooted in combating oppression and building solidarity through fighting a cause, however such an understanding fails to recognise the lived experience of the individual's impairment (Abberley 1987). Williams (1999) argued that the social model limited the understanding of disability by ignoring the embodied experience of disabled people and focuses solely the differences between disabled people and those without a disability.

The recognition and insight into the significant of an 'embodied reality' helps to shape and inform the rights movements in a number of areas (Owens, 2014). Understanding how a disability is an 'embodied reality' for individuals helped empower disabled people (and other minority groups) as it embraces the phenomenological aspects of being, the lived experience of being a person with a learning disability or a person from a minority group. Accepting the 'embodied reality' of the phenomenological body allows the lived experiences of people with learning disabilities (or other disadvantages as represented by either the medical and/or the social model) to be 'actively directed towards and interwoven within the world (Aho, 2010, p.37). Abberley (1987) expands on this concept, contending that disability is further shaped by social and economic factors such as poverty and poor living conditions. Saguna (2014) proposed that 'life is the accumulation of the complex whole, consisting of individual and societal experiences' (p.53), therefore the embodied experience of individuals must be appreciated within this practical context and incorporating engagement within the wider sociality

People with learning disabilities should be valued for their unique individual experiences, including the embodied reality of their learning disability. My research attempts to honour participants' lived experiences of relationships and understanding that there may be mind and body deficits (cognitive or lack of spoken language) which could pose difficulties within the research process however, as the social model supports, these barriers are not a reason to prevent people with learning disabilities from participating in research. Therefore, having a learning disability can be medically and/or socially constructed but is always an embodied reality for individuals. People are simultaneously restricted by society due to issues such as prejudice and a lack of

services but also as a result of the physical/cognitive aspects relating to their disability. As a researcher and social care professional, I acknowledge the embodied reality of a learning disability while also recognising that society imposes barriers to individuals which creates further disabilities which can sometimes be overcome. Mercer's (1973) 'Social Systems Perspective' defined a person with a learning disability as someone who, at some point in their lives, had been 'in receipt of specialist services specifically for people with a learning disability' (p.3). I used Mercer's definition for the recruitment criteria for the research. Participants were all in receipt of specialist learning disabilities services. Mercer's definition acknowledges the concept identified in Fyson and Kitson (2007), that participants experienced difficulties in their daily lives and required support due to their disability. This was sufficient information for the scope of my research, I did not require further details such as participants' IQ score or classification as this was unnecessary considering the scope of my research.

I chose to use the term 'learning disability' as this is the term used most widely within the world of social care where I work. I was aware that that People First (an International Advocacy Organisation for people with learning disabilities) prefers the term 'learning difficulties' (People First, no date). However, this is not widely recognised and the term is mainly in use in conjunction with educational issues unrelated to intelligence such as Dyslexia. 'Learning disability' was the most easily understood term by others outside of my profession to describe the individuals included in my research.

### **Definition for those without a learning disability**

The term 'adults without learning disabilities' was used for people within the wider population defined as not having a learning disability. This term was selected as it was considered most respectful to participants with a learning disability as it would have been inappropriate to have defined them as 'normal', suggesting people with a learning disability were not.

### **Definition of Intimacy in Romantic Relationships**

There has been much debate regarding what constitutes intimacy (Holt *et al.*, 2009) and various definitions of intimacy were considered. The relationships in this research had to be romantic in nature but not necessarily involve sexual intercourse and the definition needed to reflect this. Moss and Schwebel (1993) defined intimacy in romantic relationships as 'the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal (although not necessarily symmetrical) relationship' (p. 33). This definition was appropriate for my research as it referenced that relationships required some degree of physical

closeness (kissing, holding hands or cuddling) and a mutual commitment to each other, which was reciprocal in nature.

The next chapter critically examines the existing research literature surrounding relationships for adults with learning disabilities situated within a social, historical and cultural context, identifying what was known already on this topic, how it relates to similar research and how I conducted the literature review using the terminology defined in Chapter 1. Chapter 2 will demonstrate how research on partner selection for people with learning disabilities was absent within the literature and presents the questions and objectives I designed to explore this.

## Chapter 2- Literature Review

This Chapter critically evaluates the current literature relevant to the broad research aims outlined in Chapter 1. It commences with an explanation of how the literature review was undertaken, then discusses the social, historical and cultural influences on relationships and sexuality since the 1960s. It next examines the key characteristics of intimate relationships within wider society and concludes with an examination of the intimate relationships of people with learning disabilities and intimate relationships.

### 2.1 Conducting the Literature Review

This Section highlights how the literature review was conducted including the databases and sources accessed and why it was conducted in this fashion. The literature review utilised mainly on-line e-resources to access journal databases as well as a minimal number of printed books. The databases used for the literature review were those that focused on key areas and disciplines relevant to my research. These included psychology, sociology, social work, social policy and legislation, health and nursing. I used a combination of different databases, but the most frequently used and checked on a regular basis are outlined in Table 1.

**Table 1: Databases to conduct the literature search**

Name of Database	Range	Type of Literature
Applied Social Sciences Index and Abstracts	Health, economics, social issues and social policy, organisational behaviour and communication.	English language journals in applied social sciences
CINAHL Plus with Full Text	Nursing and allied health	International journals
Community Care Inform	Online reference tool for social care professionals working with children, young people and their families	Expert-written, practice-related information, including guidance to key pieces of legislation: case studies rewritten specifically for social care professionals; expert articles: research and practice guides.
PsycArticles	Psychology	Peer-reviewed scholarly and scientific articles



Name of Database	Range	Type of Literature
Psychology and Behavioural Sciences Collection	Emotional and behavioural characteristics, psychiatry and psychology, mental processes, anthropology, and observational and experimental methods	Full-text journals
PsycINFO	Psychology	Psychology journals, from 1974. Also contains summaries of English language Chapters and books in psychology and related disciplines from 1987
Sage Journals on-line	Online access to the full text of individual SAGE journals. The SAGE Full-Text Collections, SAGE's award-winning, discipline-specific research databases	Full-Text Database
Social Care Online (Scie)	A product of the Social Care Institute for Excellence (SCIE). Social Care Online is the UK's most extensive database of social care information	Research briefings, reports, government documents, journal articles, and websites.
Social Policy and Practice	Evidence-based social policy, public health, social services, and mental and community health. The database is particularly strong on social care of the young and elderly.	Social policy and practice is a bibliographic database with abstracts
SocIndex	The world's most comprehensive and highest-quality sociology research database. Its extensive scope and content provide users with a wealth of extremely useful information encompassing the broad spectrum of sociological study	Full-Text Database  E-Journal

(Source- LSBU Library Website)

In addition, grey literature was via government, NHS and charity/ research organisation websites.

The preliminary literature review was conducted in the first two years of writing the thesis (2009-2010) and since this time, periodic searches have been conducted on a quarterly basis to determine if any new literature had been produced which was relevant to my thesis. When new and relevant material was located it was incorporated into the literature review.

Only research from developed nations written in the English language was included in the literature review. This included research from Europe, USA, Canada, New Zealand and Australia. This was due to the difference in culture, perception and treatment of people with learning disabilities outside of this geographical location. The differences between cultures in developed nations to those in developing nations would have been too large for the data to have been comparable. There appeared to have been a trend for relationship research (for people with and without learning disabilities) to have mainly been conducted in the 1990-2000s. Older research was included in the literature review to demonstrate a historical understanding of how people with learning disabilities were viewed and treated and to gain a sense of the social, historical and cultural influences.

Due to the different terminology employed to describe people with learning disabilities, a variety of search terms were used when searching within databases.

The search terms included: Learning Disability, Learning Disabilities, Learning Disabled, Intellectual Impairment, Intellectually Impaired, Intellectual Disabilities, Intellectual Disability, Intellectually Disabled, Mentally Handicapped, Mentally Disabled, Mental Retardation, Mentally Retarded, Developmental Disabilities, Developmentally Disabled, Developmental Impairment, Developmentally Impaired and Learning Difficulties.

A variety of search terms were used to identify the relevant literature relating to relationships and partner selection. These terms were searched for in conjunction with those used to describe people with learning disabilities.

The search terms included: Relationship, Love, Loving, Loved, Marriage, Married, Commitment, Committed, Intimacy, Intimate, Closeness, Close, Affection, Affectionate, Friendship, Friends, Partner, Boyfriend, Girlfriend, Significant Other, Partner Selection, Mate Choice, Desirable Qualities, Desirable Quality, Romantic, Romantic Relationships, Sex, Sexual Relationships, Intimate Relationship, Intimate Touching, Sexual Preferences, Partner Preferences, Date, Dating and Dating Patterns.

I undertook a systematic approach to literature searching and to ensure key articles were not missed, different combinations of the search terms above were employed with Boolean Logic and truncation symbols where possible within the listed databases. From my enrolment at LSBU in September 2009 until I began interviewing participants in May 2011, searches were conducted each month on the databases in Table 1 to

ensure there was no new material. I immersed myself within the literature, developing a system where the abstracts of articles from the searches were read and relevant articles were read in full and saved to the relevant folder on my laptop. A snowballing strategy was executed: the bibliographies of relevant articles were examined for articles that related to my research question. This produced a comprehensive review of the literature relating to my research question.

Relationships occur within a social, historical and political context, so Section 2.2 contextualises the research in relation to societal changes regarding attitudes towards relationships and sexuality and the relationship to people with learning disabilities. Maslow's theory of human motivation was identified as significant in understanding development and will be discussed in Section 2.3.1. Sections 2.3.2 and 2.3.3 define and explore key concepts such as love and intimacy. The main findings of the research articles relating to partner selection for people without learning disabilities are summarised in Section 2.3.4. Attachment theory, a contrasting approach to Maslow's in understanding the development and maintenance of relationships, will be explored in Section 2.3.5.

## **2.2 Social, historical and cultural influences on relationships, sexuality and learning disability**

Intimate relationships occur within a social, historical and cultural context. For centuries, continuing until after the Second-World War (1939-1945), sexual life was linked to marriage. Society did not welcome children born outside of marriage due to the shame endorsed by the Christian Church (Koffman, 2012). Additionally, prior to the industrial revolution (approximately post 1780), society was predominantly characterised by life in rural communities that focused on the collective rather than the individual. For families with a degree of wealth or social status, marriage occurred mainly for financial reasons or for gain in familial status (Jamison, 1998). For the working/peasant classes, marriage typically occurred as the church considered it morally correct, especially if the woman was pregnant (Koffman, 2012). Post 1800, society began to place significant emphasis on the family rather than the community, freeing couples to develop intimacy within the context of a private family environment (Jamieson, 1998). The influence of society, history and culture on relationships and sexuality has been substantial since the 1920s and in the 1960s, Britain witnessed an unprecedented change in sexual attitudes and behaviours which became increasingly liberal, and this was defined as the 'sexual revolution' (Wells and Twenge, 2005).

The sexual revolution of the 1960s was seen as a rebellion against both Christian morality and sexual repression (Foucault, 1980). The introduction of the contraceptive pill to all women in 1967 had a significant impact on sexuality and relationships. The pill was revolutionary as it separated sex from procreation, increasing women's sexual freedom by affording them more control over their own fertility without sacrificing sexual relationships. Goldin and Katz (2002) argued how the effects of the pill went beyond sexual liberation and claimed that deferring motherhood increased the likelihood of women accessing higher education or employment. Increased sexual freedom led to an increase in partners prior to marriage (Schofield, 1973). This increased the number of partners which could be 'sampled' prior to marriage as there was less risk of an unplanned pregnancy. However due to restrictive social morals, the contraceptive pill was only made available to married women in Britain in 1961 due to fears of increased promiscuity (Lynch, 2005). The 1967 National Health Service (Family Planning) Act permitted local health authorities to provide birth control advice regardless of marital status to prevent unplanned pregnancy (and provided the pill free of charge from 1974). However, in 1970 only one in a hundred women had tried the pill and most people had only had sex with one or two people prior to marriage which was comparable with their parents' generation (Sandbrook, 2005). This demonstrated that Britain still remained relatively socially conservative despite changing societal attitudes. Sexual activity was curtailed by normative practices that were driven by the shame that was attributed to being an unwed mother in Britain in the 1960s (Koffman, 2012).

Faced with the shame and distress of being an unwed mother, many women sought illegal abortions. From 1955-1967 illegal abortions were the leading cause of maternal mortality in England and Wales and the main driver for legalisation was to reduce female mortality rates (Royal College of Obstetricians and Gynaecologists, 2007). The Abortion Act 1967 legalised abortion up to 28 weeks gestation. After the Act was introduced mortality rates declined, affording women a safe alternative if they wanted to terminate their pregnancy (Royal College of Obstetricians and Gynaecologists, 2007). In the 1960s and 1970s unmarried women were more likely to have an abortion due to an unplanned pregnancy, and this trend has continued to the present day (Carroll, 2007). It could be argued that from the 1960s fertility and pregnancy became increasingly medicalised due to the introduction of the contraceptive pill, the legalisation of abortion and an increase in hospital births. Home births declined from 30% in 1963 to just 4.2% in 1974 (Office for National Statistics, 2013).

People with learning disabilities were possibly less affected by changes in sexual behaviours and attitudes as a result of the pill or legalised abortions than the wider

population because many were still segregated from society in the 1960s. They remained either confined within large institutions or 'closeted in their homes with their sexual needs ignored or punished' (Kempton and Kahn, 1991, p.93). Fear persisted that people with learning disabilities would produce a child with similar disabilities. As a result, prior to 1970 some women with learning disabilities were admitted into institutions when they sexually matured to ensure they did not reproduce (Kempton and Kahn, 1991).

By the 1970s British attitudes towards sexuality became more liberal, as evidenced by the publication of *The Joy of Sex* (Comfort, 1972) which focused on sexual enjoyment and experimentation. This mainstream bestseller demonstrated that the British public was becoming increasingly open to discussing sex, both in society and within the privacy of a relationship. This was accompanied by increased sexualised imagery within society, for example, in 1970 The Sun newspaper introduced topless female models on 'Page Three', which was considered sexually graphic for the mainstream press (BBC, 2010). This relaxation in attitudes towards sex began to be extended to people with learning disabilities. There was recognition in this period that they also had the right to have sex and relationships, and training surrounding this was developed (Wolfensberger, 1972 and Kempton and Kahn, 1991). Sex education training in the 1970s showed a bias towards heterosexual relationships and focused on contraception as it was clearly stated that people with learning disabilities should not procreate (McCarthy, 1999). Marriage was promoted for people with learning disabilities, reflecting more traditional values (McCarthy, 1999). This demonstrated that attitudes had begun to relax but co-habitation, parenthood and homosexuality remained less acceptable.

The 1980s witnessed a partial return to traditional values within society during a climate of new moral conservatism under Margaret Thatcher's Government and fuelled by media hysteria surrounding AIDS. In 1982 the first British person died from AIDS-related complications and the disease became linked to intimate sexual contact, as well as contaminated needles or blood products (Morbidity and Mortality Weekly Report, 1983). The UK media contributed to a climate of fear and moral panic, denouncing it as a 'gay plague' and linked the virus to promiscuous sexual behaviour (Halifax, 2011). Thatcher's Government legitimised society's prejudice towards homosexuals by introducing Section 28 of the Local Government Act 1988 which prohibited the promotion of homosexuality in schools. In 1987, the Government instigated a public health campaign '*Don't Die of Ignorance*' to combat the spread of the disease, demonstrating that AIDS was a threat to everyone. The AIDS epidemic changed British

society as it brought sex into public discourse. This was evidenced by public discussions regarding sex and contraception, 'wholesome family' television presenters demonstrating how to use condoms on primetime television (BBC, 2005), a heterosexual HIV positive character was introduced to EastEnders (a primetime television show) and a gay/ lesbian TV series 'one in five' aired on Channel 4 (Stonewall, no date). The outbreak of AIDS and anti-gay legislation under Thatcher's government assisted in mobilising the gay community's collective resistance such as establishing the Stonewall Group to oppose Section 28 and other issues regarding equality for lesbians and gay men (Stonewall, no date). This highlights how the 1980s was an era where negative stereotypes surrounding sexuality and difference were being challenged.

The Disability Rights Movement also gained momentum in this period and began to influence society and politics through campaigning for equal citizenship for disabled people. Examples of these campaigns included equal access to transport, education and employment, and an end to segregation from society and discrimination on the basis of disability (Shakespeare, 1993). Rights campaigners for people with learning disabilities were influenced by the principle of 'Normalisation' (Wolfensberger, 1972, 1983), the belief that individuals should experience a life similar to the general population. There was a movement to close long stay learning disability hospitals and for people to be resettled in the local community (this will be discussed further in Chapter Six). Despite this progression in attitudes, the Jay Committee Report *Care of the Mentally Handicapped* (1979) reported that 40% of hospital and care staff felt that people with learning disabilities should be sterilised and this was a strong theme in the literature between 1987 and 1989 (McCarthy, 1999). Despite this attitude, in the 1980s sex education was increasingly provided to people with learning disabilities and their support staff, and they began to receive educational packs relating to sexual education for people with learning disabilities (McCarthy, 1999). Statutory and voluntary organisations were obligated to devise policies which addressed sexuality, implying that society was beginning to become more open to sexuality for all people, including those with learning disabilities. Although the experience of people with learning disabilities regarding sexuality and relationships in the 1980s appeared to be changing, in reality, little had changed for many people since the early 1960s.

McCarthy (1999) highlighted how, prior to the 1990's, same sex relationships for people with learning disabilities were excluded from educational literature related to sexuality aimed at support providers, educators or social workers. However, in the 1990's educational material began to include references to same sex couples (McCarthy,

1999). This was reflective of the increasing acceptance of same sex couples in mainstream culture. Under a 'New Labour' Government in 1997 various progressive changes in legislation occurred, such as in 2000 the legal age of consent for homosexual sex was reduced to 16 years old, which was equal to heterosexual relationships, and Section 28 was abolished in 2003. Under the Conservative-Liberal Democrat Coalition Government same sex marriages became legal in March 2014.

However, more liberal attitudes continued to be less evident in relation to people with learning disabilities. Fitcher's (2011) evidenced-based review of the practice literature post 2000 identified a consensus among older or religious staff to maintain more conservative views regarding sexuality for people with learning disabilities. For example, homosexuality and sex outside of marriage were considered less acceptable (Cuskelly and Bryde, 2004, Swango-Wilson, 2008). Staff can have a significant impact on the lives of the people they support which means that conservative staff may not have empowered people to engage in relationships of their choosing as directed by *Valuing People* (DoH, 2001). Fitcher's (2011) article commonly cited research that was over ten years old. As such, it is possible that attitudes may have altered since that time. McCarthy's (2009) research also highlighted conservative attitudes towards people with learning disabilities in relation to parenthood, as evidenced by the contraceptive injection Depo-Provera being disproportionately used for women with learning disabilities compared to the wider population. McCarthy (2009) argued that this practice has been perpetuated to give 'providers control over clients' choice' (McCarthy, 2009, p. 203). The fertility of women with learning disabilities appeared to be highly medicalised and over-regulated by professionals out of fear of pregnancy. For women without learning disabilities access to the contraceptive pill (and other non-barrier methods of contraception) has often been seen as empowering, enabling them to take control of their own fertility (Goldin and Katz, 2002). However, for some women with learning disabilities arguably the reverse was true, as it possibly disempowered them in terms of protection from sexually transmitted diseases and the option of parenthood. At the same time, it may have increased their sexual freedom as staff may have encouraged relationships more if they perceived the risk of an unplanned pregnancy as lower.

In addition to the philosophical internalised changes in attitude, British society has been influenced by external changes such as immigration. Prior to the 1950s most immigration to the UK was from Ireland (Ghail, 2000). The 1948 British Nationality Act allowed any subject of the British Empire the right to live in Britain. The 1948 Act resulted in large scale immigration from commonwealth countries such as India,

Pakistan, the Caribbean Islands (West Indies) and West Africa (Bloom and Tonkiss, 2013). Most notably, in June 1948 the *'Empire Windrush'* docked in Tilbury carrying 495 Jamaicans wanting a new life in Britain (Mole, 2001). Post World War Two, immigration was encouraged as it assisted Britain in rebuilding its industries and helped to replace a depleted workforce (Bloom and Tonkiss, 2013). In the 1960s the Department of Health directly recruited people from the West Indies to work in the health and domestic services (Layton-Henry, 1985). The 1962 Commonwealth Immigrants Act was passed to address public concerns regarding increased immigration which restricted opportunities for those with no direct UK ancestor (Bloom and Tonkiss, 2013). However, by 1980 there were 2.1 million people of New Commonwealth (ex-colonised developing non-white countries) and Pakistani descent living in Britain (Office of Population Censuses and Surveys, 1981). The late-1990s witnessed another significant rise in immigration to the UK (Park *et al.*, 2012). The adoption of the Asylum and Immigration Appeals Act 1993 and the incorporation of the European Convention for Human Rights (1998) meant that asylum seekers increased threefold from 1996 to 2002, with 85,000 asylum seekers in the UK in 2002 (Blinder, 2011). In 2004, eight eastern European countries joined the European Union including Romania, Bulgaria and Poland. The UK was one of only three countries to not impose immigration restrictions, resulting in a substantial increase in Eastern European migrants (Park *et al.*, 2012). The inflow of EU citizens (excluding British citizens) to the UK for 1997-2003 was 67,000 which rose to 170,000 from 2004-2012 (Vargas-Silvia, 2014). Net annual immigration figures for the year ending March 2014 were 243,000 (Office for National Statistics, 2014).

Circumstances have highlighted that not all British citizens and migrants share the attitudes described in the Equality Act 2010 and that the UK's position on tolerating beliefs which contradict its laws and values may be unsustainable. An increase in immigration increased the diversity of culture but not all immigrants' countries of origin share British attitudes in relation to sexuality and relationships. For example, in 2015 there are 78 countries in the world where homosexuality remains illegal, including 38 African countries and Commonwealth countries such as India, Bangladesh, Sri Lanka and Jamaica. In 2015 there were seven countries in the Middle East and Africa where homosexuality is punishable by death (AVERT, no date). Attitudes towards pre-marital sex differ across countries and many are not as accepting as Britain, with pre-marital sex considered unacceptable by almost '90% of respondents in predominantly Muslim countries such as Indonesia, Pakistan, Turkey, Egypt and Tunisia' (PewResearch, 2014). African countries such as Nigeria, Ghana and Uganda demonstrate similar levels of disapproval (PewResearch, 2014). Since 2000, there has been an increase in the



number of care workers recruited from outside the UK; between 2001 and 2009 the proportion of foreign-born care workers rose from 7% in 2001 to 18% in 2009 (Cangiano and Shutes 2010). Most of these workers came from countries such as Poland, the Philippines, Zimbabwe, India and Nigeria (The Migration Observatory, 2011). A review of the literature was unable to identify research which explored how the culture, social and religious values of staff from countries, such as those in Africa and Asia, influence the support they provide to people with learning disabilities regarding sexuality and relationships. However, considering the differences in values and culture described between such countries and the UK, it could be hypothesised that its effect would not be positive in terms of progressing attitudes towards sexuality for people with learning disabilities. For example, since 2004, there has been an increase in eastern European migrants who found employment as unskilled workers in social care (Vargas-Silvia, 2014). Undercover reporters in Romania found squalid institutions, with poorly stimulated people who claimed to have been abused (Spiller, 2014). It is unclear how eastern European staff may have been influenced by any prior experience of working with people with learning disabilities in their own country.

In conclusion, people with learning disabilities, unless residing within institutions, inhabit the same social world as people without learning disabilities. However research suggests that they do not experience the same freedoms as other citizens. Legislation or significant events which empowered people without learning disabilities, such as the introduction of the contraceptive pill or abortion, have been utilised to disempower people with learning disabilities to some extent. Staff from countries which typically hold conservative views in relation to sexuality and relationships may have reservations in supporting people with learning disabilities to express their sexuality and engage in relationships. There is evidence that attitudes are changing, but learning disabled people still appear to be far behind the general population in terms of freedom to express their sexuality and engage in relationships freely of their choice.

## **2.3 Characteristics of Intimate Relationships**

The previous Section set the scene for what is considered acceptable within society in regards to relationships. The following Section examines the development of intimate relationships in light of Maslow's theory of human motivation. This includes the concept of love, arguably the most fundamental aspect of intimate relationships, then continues by examining the core components of love, including intimacy and attachment, as these components were cited most frequently as significant within research on love and relationships as identified from the literature review.

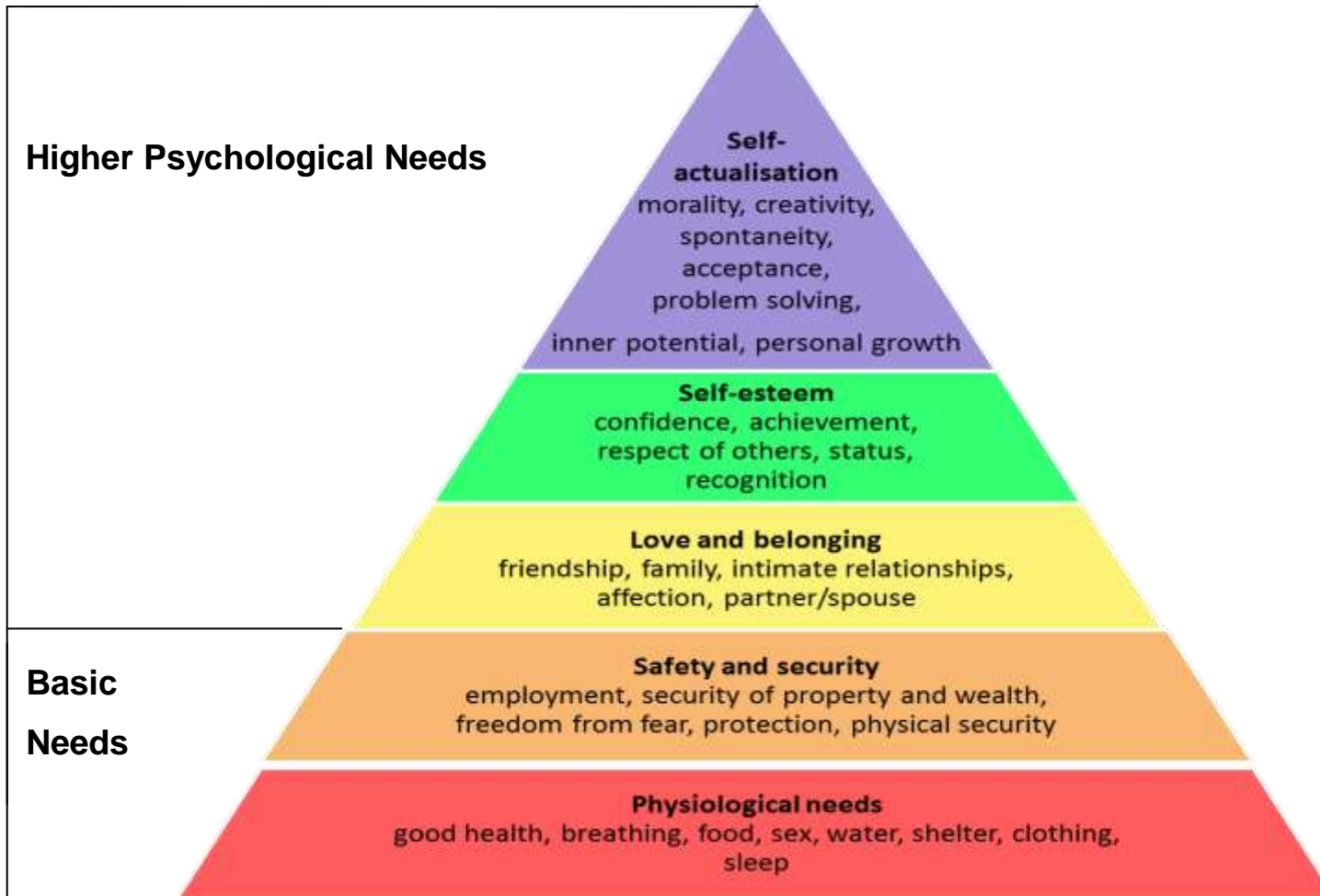
### **2.3.1 Maslow**

Maslow's (1943) humanistic theory of human motivation has been influential within the human sciences and has been extensively applied to a range of human fields of exploration (Cullen and Gotell, 2002). Maslow's (1943) 'Hierarchy of Needs' proposed that humans were motivated to reach their potential (self-actualisation) through meeting various needs in ascending order. In order to attain 'love and belonging' individuals had to first satisfy the lower 'basic needs'. Considering the issues faced by people with learning disabilities, attaining such 'basic needs' could prove problematic. According to Maslow, this would hinder their ability to experience loving relationships. Various representations of Maslow's model were freely available on-line, which I evaluated and then formulated my own interpretation based on Maslow's theory in relation to my research (Figure 1 A).

Maslow considered 'basic needs' to be the 'physiological needs' and 'safety and security needs'; 'higher psychological needs' included 'love and belonging' and 'self-esteem'. Maslow's theory of human motivation (1943) and the various 'needs' are discussed throughout the thesis, therefore, wherever Maslow's theory is stated this refers to his 1943 theory and the 'needs' refer to those in Maslow's (1943) hierarchy of needs as outlined in Figure 1A.

Maslow (1943) proposed that humans had to satisfy basic physiological needs, which were fundamental to survival. Maslow argued that individuals who had had their 'basic needs' met in early childhood 'seem to develop exceptional power to withstand present or future thwarting of these needs simply because they have strong healthy character structure as a result of basic satisfaction' (Maslow, 1943, p.387-8). Sex was considered a 'basic need', however the Family Planning Association (FPA) highlighted how people with learning disabilities experience barriers to sexual relationships (FPA, 2008) which will be discussed in Section 2.4.3. Also people with learning disabilities in supported accommodation experience poor nutrition with less than 10% eating 'a balanced diet, with an insufficient intake of fruit and vegetables' (Emerson and Baines, 2010, p.8). However a person with a learning disability who is known to statutory services is usually afforded some protection from homelessness and starvation as adult social care services would be obligated to take appropriate action if any safeguarding concerns were reported.

Figure 1A: Maslow's Hierarchy of Needs



Another 'basic need' and the second level of Maslow's hierarchy is 'safety and security needs'. Maslow (1943) did not believe that individuals are at risk of danger, claiming that a 'good society ordinarily makes its members feel safe enough (p.379). However, this may not be the experience of people with learning disabilities who experience higher levels of abuse than the general population (McCarthy, 1999) and will be discussed in Section 2.4.5. Some people with learning disabilities experience 'disability hate crime' due to being disabled. There was an increase in the number of reported crimes in 2012/13 compared to 2011/12 rising from 1,757 to 1,841 (Home Office, Office for National Statistics and Ministry of Justice, 2013), but it was unclear how many cases specifically related to people with learning disabilities. There have been several recent high profile abuse cases involving people with learning disabilities perpetrated by staff/ organisations employed to protect them, including those examined in the *Serious Case Review into Winterbourne View* (Flynn, 2012) and the case of 'Lisa' highlighted in the Care Quality Commission's (CQC) report '3 Lives' (CQC, 2014). 'Lisa' was detained for nine years in seclusion on a male ward in a secure hospital. It was possible this was to 'protect' her from males on the ward, but it was still clearly wrong and abusive. This implies that in terms of their 'safety and security needs', people with learning disabilities experience more challenges than the general population. Additionally, people with learning disabilities experience a greater risk to their 'safety and security needs' due to experiencing high levels of poverty and poor quality housing (Emerson *et al.*, 2005), as well as high unemployment (DoH, 2009).

'Love and belonging' is the third level of Maslow's hierarchy and is considered a 'higher psychological need'. Maslow considered relationships important: 'the ones who have loved and been well loved, and who have had many deep friendships who can hold out against hatred, rejection or persecution' (Maslow, 1943, p.388). Maslow's theory was goal orientated and he considered love as an important process to facilitate self-actualisation. People with learning disabilities experience significant issues in regards to intimate or sexual relationships (McCarthy, 1999, FPA, 2008). Section 2.4 contains a complete examination of research regarding relationships and people with learning disabilities. People with learning disabilities often lack close friendships and experience increased social isolation (DoH, 2009). They are less likely to have contact with friends compared to the general population (Emerson and Hatton, 2008) and this is more prevalent in older people with a learning disability (Emerson *et al.*, 2005). A lack of close friendships and relationships suggests that their 'love and belonging needs' are not being met. Maslow (1954) proposed two types of love: deficiency love (D love) and being love (B love). D-lovers are selfish and possessive and seek a partner who fulfils their unmet needs for example status. B lovers are less selfish in their giving of love

and seek a more equal partnership. However, Maslow had no empirical evidence to substantiate this theory (Dietch, 1978). A search of the literature using 'Maslow' and 'deficiency love and/or being love' as search terms only identified one article which utilised his concepts in research that focused on sexual addiction (Reed, 2000). An interpretation of Maslow's theory is that people with learning disabilities who fail to have their 'basic needs' within the hierarchy met could potentially fail to attain B love with a partner.

The penultimate hierarchy level is 'self-esteem needs', which focus on having confidence, the respect of others, social status and recognition. Research indicates that people with learning disabilities typically fail to acquire socially valued roles which are associated with high self-esteem. Being employed is associated with increased self-esteem (Sheeran and McCarthy, 1990) and 65% of people with learning disabilities wanted to be employed in one study (DoH, 2009). However, in 2011/12 only 7.1% of British people with learning disabilities were in paid employment (Emerson *et al.*, 2012). Other socially valued roles include being a parent, however research has highlighted that people with a learning disability often face issues regarding parenthood and 50% of parents with a learning disability have had their children removed into care (Tarleton *et al.*, 2006). Autonomy is important in Maslow's model, but this remains an issue for many people with learning disabilities (DoH, 2009). People with learning disabilities have experienced significant challenges to their autonomy which will be discussed in Section 2.4 and Chapter 6. The lack of people with learning disabilities in positions of authority or those with socially valued roles suggests that they would experience difficulty in attaining this level of the hierarchy.

Self-actualisation was the goal of Maslow's theory, and he described the people who attained this state as creative, spontaneous, satisfied, accepted and fulfilled their potential. Based on the issues discussed in this Section, it would be unlikely that many people with learning disabilities would attain this. There appear to be too many barriers at each stage of the hierarchy for them to reach their full potential and some possibly remain at the lower levels of the hierarchy and, according to Maslow, fail to develop intimate relationships.

Maslow's theory was published in 1943, and since its conception there have been significant social, cultural and historical changes in Britain, as outlined in Section 2.2. Maslow's theory provides an explanation of the historical view of relationships which places limited significance on love and primary significance to the security and social status associated with relationships. It could be argued that Maslow's theory is

individualistic, and a major flaw is possibly its lack of recognition that 'needs' are not solely individualistic and others also have 'need requirements', and an individual's ability to meet their needs could be due to economic circumstances beyond their control. Maslow's theory was published in the USA during World War Two after the greatest depression in history. By the mid-1940s the depression had ended and a period of prosperity began (Clausen, 1995). The memory of such poverty and unsettlement could explain why Maslow afforded such significance to self-improvement, achievement, social status and security in relationships as opposed to love. The lack of a supportive welfare state, such as that which began in 1948 in the UK, is also significant. A welfare state afforded some security to individuals that their basic needs such as food and shelter could be met.

Maslow's view appeared to contrast with modern day concepts of relationships in developed nations where love and intimacy are considered to be the most important components (Sternberg, 1996, Graham, 2011). The significance afforded to love and intimacy in relationships in relation to his theory will be discussed in the next Section.

### **2.3.2 What is Love?**

Love is an abstract concept and unique to individuals. Various attempts have been made by researchers to define love, resulting in different definitions and measures. Graham (2011) conducted a meta-analysis which explored these. Triangular theories of love have been popular, suggesting love was comprised of different components to make a whole. Two of the most influential theories were Rubin's (1970) and Sternberg (1996).

Rubin (1970) defined love as having three elements: first was attachment, the desire to be close to another; second, the desire to care by putting another's needs first, and finally intimacy, including exclusivity within the relationship. Based on this, Rubin (1970) devised two questionnaires to measure loving and liking which he determined to be different concepts. Both scales produced reliable results across nationalities (Graham, 2011). Masuda (2003) argued that both components of the loving and liking scales actually constituted compassionate love, defined by Underwood (2008) as love which 'focused on the needs of the other' (p.3).

Sternberg's (1996) triangular theory of love also claimed love has three components which were intimacy, passion, and decision/commitment this appears similar to Rubin's (1970) theory with the exception of passion. Sternberg collated data from other

researchers including Rubin (1970) to define his components. He defined intimacy as 'feelings of closeness, connectedness, and bondedness in loving relationships' (p.314). Passion was the second component, defined as 'the drive that leads to romance, physical attraction and sexual consummation' (Sternberg, 1996, p.315). Decision/commitment was the final component, defined as the decision to love a person and the commitment to the relationship. All three components occur in relationships, but the significance of each component determines the type of relationship experienced. Sternberg (1996) acknowledged that although his scale produced high reliability and validity ratings, it alone was not sufficient to measure the complexity of love. Sternberg believed it needed to be combined with other theories which measured the influence of attachment such as Shaver *et al.* (1988), which suggested that early childhood experiences with primary caregivers impacted on individual adults' experience of love.

Graham's (2011) meta-analysis revealed the vast number of measures which have been applied to love. According to Graham (2011), the most accepted conceptualisation of love is that of passionate and companionate love (Berscheid and Walster, 1978). Berscheid and Walster (1978) defined passionate love as having a physiological/sexual component, an intense desire to merge with another, subject to strong emotions (negative emotions also such as jealousy/anxiety, as well as the positive) which was short-lived. They defined companionate love as less emotionally intense, associated with positive emotions such as tenderness and affection. Berscheid and Walster (1978) argued that passionate love occurs early in relationships and, if the relationship progresses, it could develop into companionate love. Sprecher and Regan (1997) supported this, claiming that passionate love decreases over time.

Buss (1994) believed that both types of love had different evolutionary functions: passionate love was what drove couples together to have intercourse to produce offspring, and companionate love was what kept them together to nurture them. Biologically, love can partly be defined as a change in a person's chemistry: at the start of a relationship there is an increase in the body of hormones such as adrenaline, serotonin, phenylethylamine and testosterone (which increases the sex drive) (Marazziti *et al.*, 1999). The endocrinal change is short-lived, returning to normal within two years: as the relationship develops typically oxytocin levels rise, which is the hormone responsible for pair-bonding (Marazziti *et al.*, 1999). This appears representative of sex as a 'basic physiological need', as defined by Maslow's theory which distinguished love from sex within his hierarchy (Figure 1 A).

Lee (1973) proposed that 'love' was not 'one' thing but that it manifested in different styles based on individual circumstances. He defined six loves styles based on those suggested by the Ancient Greeks. These styles included: 'Eros (passionate, erotic love); Ludus (love as a game, love as a series of conquests); Storge (companionate, friendship-based love); Pragma (logical, practical love); Mania (obsessive, possessive, dependent love), and Agape (selfless love, putting the other before oneself)' (Graham, 2011, p.750). Maslow's (1954) D love appears comparable to Mania and his B love shares similarities with Agape. Eros reflects the 'physiological need' of sex in relation to Maslow's hierarchy. Lee's (1973) love types share commonalities with other definitions (Rubin, 1970, Berscheid and Walster, 1978 and Sternberg, 1996). Pragma was the only style not included by another scale or definition. A 'love attitude scale' (Hendrick and Hendrick, 1986) tested the reliability of Lee's (1973) love styles and found them reliable.

Graham's (2011) meta-analysis concludes that the majority of the main love measures contain components associated with passionate and companionate love. Sternberg's triangulation theory (1996) concurred, identifying that the passion element may decrease over time while intimacy and commitment increases. Graham's (2011) meta-analysis results differed from many other results by arguing that love had a positive correlation with relationship length. This challenges the results of Hatfield *et al.* (2008) in claiming that established couples possess higher amounts of companionate and passionate love compared to newlyweds. Graham (2011) acknowledged that these results occurred as relationships lacking in love would have been terminated earlier. Sprecher and Regan (1997) identified that both forms of love occurred in relationships of varying lengths and were highly interrelated. This was also consistent with Rubin's (1970) 'liking and loving'. Unexpectedly, feelings of sexual intimacy correlated higher with companionate love compared to passionate love.

This research on love focused solely on studies from Western countries and only included heterosexual and monogamous relationships, and this could be applied and was comparable to my participants. In summary, love was found to be difficult to define: different researchers held some contrasting and comparable views, arguing whether there were different types of love and, if so, how long they lasted and if they could occur concurrently. Despite the differences in definition there were common components which included an innate desire for a union with another and a level of reciprocity combined with a willingness to act selflessly for another with some degree of sexual attraction and passion exclusively for the object of your affection.



Section 2.3.2 explained the key theories surrounding love, yet the theories made limited reference as to why love was important beyond evolutionary factors (Buss, 1994). Maslow (1943) considered love to be important and it was a recognised level on his 'Hierarchy of Needs' (Figure 1 A). Maslow stated that unless individuals attained this level they would fail to reach higher levels such as 'self-esteem needs' and 'self-actualisation'. Subsequent research has demonstrated the importance of being married or in a long term relationship. In regards to the benefits, love has been associated with economic advantages (Chun and Lee, 2001), increased mental wellbeing (Blanchflower and Oswald, 2004) and better physical health (Waite, 1995). The research did not state if the couples considered themselves 'in love', however, Sprecher and Regan (1997) and Graham (2011) demonstrated that couples in long term relationships experienced high levels of both companionate and passionate love. The review of the literature was unable to identify research which considered the importance of love for people with learning disabilities, or if this group experience any benefits as a result of being in a loving relationship.

### **2.3.3 Understandings of Intimacy**

Intimacy is a fundamental aspect of love (Rubin, 1970, Sternberg, 1996). 'Satisfying intimate relationships were one of the most important sources of delight and purpose in life' (Thelen *et al.*, 2000, p.223). However, there continues to be debate surrounding what defines intimacy. Jamieson (1999) attempted to define what intimacy meant to individuals and suggested that couples were searching for a 'pure relationship', defined as 'opening out to each other, enjoying each other's unique qualities and sustaining trust through mutual exposure' (p. 477). Other researchers such as Love and Robinson (1994) argued that no definitive definition of intimacy is possible. Intimacy was not explicitly discussed in Maslow's theory (1943), however his description of B Love (1954) contained elements relating to intimacy such as non-possessiveness and giving. My review of the literature suggests intimacy involves elements of equality, commitment and closeness between two individuals.

Holt *et al.* (2009) stated that intimacy was made up of components which together form a 'closeness' through a combination of intellectual, physical or emotional elements. They devised the Holt Relationship Intimacy Questionnaire in an attempt to establish what intimacy is and what it means to couples. The questions focused on mutual sharing of ideals, beliefs, feelings, values, goals, physical affection, reciprocity and openness. Holt *et al.* (2009) established three types of intimacy: intellectual intimacy that centred on shared goals and problem solving; physical intimacy that focused on

the physical and sexual aspects of a relationship; and emotional intimacy that centred on 'mutual accessibility, naturalness, non-possessiveness and a commitment to the relationship' (p.149). Holt *et al.*'s (2009) questionnaire could be criticised for its attempt to use a numerical rating scale to quantify something as subjective as emotions and feelings, but this was not acknowledged in their report. There were, however, questions for couples that facilitated a discussion to broaden their understanding and the focus was not solely on the questionnaire. Sprecher and Regan (2002) demonstrated how individuals moved between different levels of intimacy and this was not static. They claimed that individuals selected attributes dependent on the level of intimacy required from the relationship. However, the sample limited the applicability of this research as it only included students and the attributes valued as a young person may be very different to someone in middle/old age.

Within the research literature it is widely acknowledged that it is possible to have intimacy without a sexual relationship but not all sexual relationships were intimate (Rasmussen and Kilborne, 2007, Purnell, 2008). Research has suggested that emotional rather than physical closeness leads to intimacy within relationships. Rogge and Bradbury (2006) advocated that effective communication enables the development of intimacy. Lerner (1990) proposed that a shared history and experiences increase intimacy. Both Rogge and Bradbury's (2006) and Lerner's research (1990) implied that a shared sense of language, understanding and history increase emotional intimacy among couples. Jamieson (1999) supports this but also argued that physical activity between partners could increase intimacy as long as they have strong emotional bonds.

Relationships with high levels of intimacy are happier, more fulfilling and stable (Eckstein and Goldman, 2001). There were, however, couples who were unable to reach this level of intimacy due to a fear of intimacy. Thelen *et al.* (2000) explored how this fear affected relationships by using a 'Fear of Intimacy Scale' and a 'Personal Assessment of Intimacy in Relationships' to explore levels of intimacy in a couple's relationship and their desired level of intimacy. They concluded that although men were more likely to have a fear of intimacy, women with a fear of intimacy were more likely to end the relationship because of it. The research did not identify why individuals feared intimacy. Thelen *et al.*'s (2000) research linked a fear of intimacy to poor attachment in childhood but they did not explore this, possibly due to a methodology that did not allow that type of exploration.

In light of the lack of research literature available it is unclear if people with learning

disabilities define intimacy in the same way as non-disabled adults. Numerous questions on the Holt *et al.* (2009) questionnaire centred on discussion between partners regarding shared goals and aspirations. Many people with learning disabilities have issues surrounding verbal communication and expression of abstract concepts (McCarthy, 1999). Considering this, it is unclear if they would be able to reach the same level of mutual disclosure required for intellectual intimacy as adults without a learning disability. It is possible that, where verbal communication is an issue, other aspects of intimacy such as physical and emotional intimacy become more important to couples with a learning disability as an indication of having intimacy in the relationship.

In conclusion, intimacy is a key component of love, defined as 'closeness' between two individuals that was reciprocal and equal. Arguably, without intimacy in a relationship, love could not develop. Intimacy presents itself in different forms, such as emotional, physical or intellectual intimacy, and most relationships involve a combination of these. Sexual relationships do not necessarily lead to intimacy but could increase intimacy if an existing emotional connection was present. Couples with high levels of intimacy experience happier and more successful relationships, however, poor attachment in childhood (discussed in Section 2.3.5) suggests that relationships which develop in adulthood from this basis are likely to lack intimacy.

#### **2.3.4 Partner Selection Research**

A typology was undertaken which examined research into partner selection by non-learning disabled people (see Appendix 1). Intimacy was fundamental to successful loving relationships, and it is the ability to be kind and considerate which enables intimacy and love to develop between couples. Kindness and consideration was valued as important by both sexes. There is no literature available which explores whether people with learning disabilities value this in a partner, however considering the high levels of abuse they have experienced in relationships (McCarthy, 1999), the assumption is that this is something that would be valued highly. In relation to Maslow, this suggests individuals desire a partner who was not a challenge to their 'safety and security needs'.

Men valued the physical appearance of a partner more highly than women, however over time aesthetics appeared less important than a 'pleasing disposition' (Shackelford *et al.*, 2005). Women also displayed some gender stereotypical responses, with more women than men citing 'dependability and financial security' as a desirable trait, which suggests that despite the advances in society outlined in Section 2.2, there is still a

desire for men to provide for the female economically. This reflects Maslow's historical view of relationships, with primary significance afforded to security and social status as opposed to love.

In summary, despite some limited challenges to Maslow's historical view of relationships, love and intimacy appear to be most significant in the formalisation and maintenance of relationships. Subsequent reading surrounding love and intimacy identified how significant attachment is in developing and sustaining relationships, as both were considered key components of attachment. Attachment theory will be discussed in Section 2.3.5.

### **2.3.5 Attachment**

#### **Attachment in Childhood**

An individual's first important relationship is between themselves and their primary caregiver. Bowlby (1969, 1973 and 1980) suggested how significant childhood experiences are in forming attachment relationships, arguing that children who lack a secure attachment with their primary caregiver suffer distress when separated. Ainsworth and Wittig (1969) defined attachment as a mother who provided a secure base: 'a place of safety, comfort and warmth when anxiety levels rise' (p. 112). Ainsworth and Wittig (1969) suggested children require this security to be able to engage and explore the world without anxiety. If unable to do this, the child would not be securely attached, predicting that as a result social relationships would suffer and/or fail to develop and that an unresponsive/ emotionally/ physically unavailable caregiver leads to insecure attachments in both childhood and adulthood. Ainsworth *et al* (1978) identified three patterns of attachment: secure, avoidant and anxious/ ambivalent. Securely attached infants feel confident that their mother would be available to meet their needs. Avoidant attached infants do not seek contact or comfort. Anxious/ambivalent attached infants are preoccupied with their mother's availability due to her inconsistency (Otway and Carnelley, 2013).

Ainsworth and Wittig's (1969) theory centres on an observational experiment 'the strange situation': children were placed and observed for distress in an unfamiliar setting for twenty minutes while strangers and their mother entered and left the room at intervals. Under current guidance, this research would be considered unethical due to the potential levels of distress experienced by the children and caregivers. The experimental design was also criticised for allowing just twenty minutes of observation

and Rutter (1995) argued that longer periods of more naturalistic observation would have enabled a deeper understanding of the child's attachment relationships. Other variables could have affected the child on the day of the experiment, such as their mood. Cultural differences were apparent, such as in Japan where infants rarely separated from the mother (Miyake *et al.*, 1995). However, Van Ijzendoorn and Kroonenberg (1988) demonstrated similar results in a wide range of countries.

Controversy arose as both Bowlby and Ainsworth's research focused exclusively on the mother-infant bond (Hrdy 2005). Feminists claimed this perspective was an argument to keep women out of the work force and remain dependent on men. Feminists agreed it was important for children to be cared for, but they argued that this could occur within a family context, sharing the care among a group of male and female adults (Howe, 1995). Research has demonstrated that the quality of the relationship with the main caregiver has more influence on development than mere presence. Howe (1995) confirmed that attachment had to include warmth, reciprocity and a caregiver who responded consistently.

Bowlby's (1944, 1969 and 1973) theories significantly influenced how researchers understood attachment. Bowlby's (1944) research '44 thieves' was conducted to support his theory. This involved interviewing children referred to a child protection programme due to stealing, as well as a control group referred for emotional problems, to determine if they had suffered maternal deprivation. Bowlby's theory implies that if the maternal bond was broken in childhood this would result in poor intellectual, social and emotional development. Bowlby (1944) concluded that over 80% of 'thieves' had been separated from their mothers for over six months during their first five years compared to 20% of those who had not committed a crime. Bowlby reported that 32% of 'thieves' demonstrated 'affectionless psychopathy', which was classified as being unable to care about/feel affection for others or form relationships. Bowlby claimed this was due to maternal deprivation in childhood. However, the research was possibly affected by experimenter bias as Bowlby interviewed and diagnosed all of the participants himself. In addition, the participants recalled their early experiences, and their ability to recall such experiences accurately may have been limited. The research only explored maternal deprivation: other variables such as income, paternal relationships or education that could have affected the individuals were ignored (McLeod, 2008).

Bowlby (1951) submitted his report '*Maternal Care and Mental Health*' as part of the United Nations' programme for the Welfare of Homeless Children, and it warned that

children who experienced maternal deprivation, especially those brought up in institutional care, had poorer emotional, intellectual, verbal, social and physiological development. Bowlby (1951) suggested that such individuals found it difficult to form stable relationships in their adult lives. Rutter (1981) criticised Bowlby's report concluding that the children had never experienced maternal care, defining this as 'maternal privation', due to moving frequently during childhood and he argued that it was this that had a more devastating impact on children than maternal deprivation.

Hodges and Tizard's (1989) longitudinal research followed sixty-five children in residential nurseries where nurses provided care but were discouraged from forming attachments. This highlights how individuals growing up in institutional care are more likely to experience difficulties in social relationships especially with their peers, but they were not able to state that this was exclusively the cause: other factors such as poor diet and lack of stimulation could have affected development (McLeod, 2008). The research also experienced a degree of attrition with nine of the original participants failing to take part in later stages. It was possible that the participants who refused to take part were experiencing significant difficulties, which could have affected the results (McLeod, 2008). Lieberman and Pawl's (1988) findings concurred with Hodges and Tizard's (1989), concluding that attachment disorders are more common in children raised in institutions. Based on the requirements for a secure attachment it was unlikely that children received the consistency of care required for secure attachments due to the turnover of staff. The focus of staff within institutions is primarily to care for children, making all social interactions based on need (Howe, 1995). As a result, children experience less individualised contact, as staff would be unable to show them the level of interaction and affection that one would with their own child.

Rutter's (1981), Lieberman and Pawl's (1988) and Hodges and Tizard's (1989) research is particularly relevant when considering people with learning disabilities, many of whom grew up predominantly in some form of institutional care prior to the closure of the large-scale institutions in the 1980s (French, 2010). A search of the literature was unable to produce a definitive number of how many children/young people with learning disabilities lived away from the family home in either institutions or residential schools prior to the institutional closures in the 1980s. However, contemporary figures demonstrated that in 2004, 8,500 children with complex physical and learning disabilities attended residential special schools (Paul *et al.*, 2006). Although these residential schools were not hospitals, they were still institutions away from the family environment.

Research has been conducted which suggested that children with learning disabilities who historically grew up outside the family environment experienced isolation and were deprived of love and individual attention. French (2010) shared experiences of staff working as 'housemothers' in a residential school for children with learning disabilities in the 1960s. She identified how staff and children often lived in rural isolated settings: children were required to follow strict regimes with little time to play due to the care needs of the many children and with a lack of staff, who may also have been young and frequently untrained/unqualified. French (2010) explained how staff witnessed direct and indirect abusive practices, including restrictive physiotherapy and overt cases of physical abuse. Other researchers such as Stanley *et al.* (1999) and French *et al.* (2006) highlighted the number of abuse scandals that were common within residential institutions in the 1960s. French's (2006) research could be criticised for only including the perspectives of three young women working within a single institution. The author herself had worked there and was reflecting her experiences. It was unclear what motivated the other two women to take part, how they were selected or what their relationship with the researcher was. The inclusion of more than three staff members, and possibly including staff with different perspectives such as psychologists, may have produced a more varied and balanced understanding of the experiences within the school. It was also possible that this school was different to other similar establishments in terms of practice and culture. However, despite the small sample, there are comparisons between French's (2010) findings and others, even in different countries and timescales such as Hreinsdottir and Stefansdottir (2010) in Iceland in the late 1960s-1970s. Poor conditions in institutions were reported in various reports such as at Ely Hospital in Cardiff (Department of Health and Social Security, 1969), Farleigh Hospital (Department of Health and Social Security, 1971) and South Ockendon Hospital in south west Essex (Department of Health and Social Security, 1974), which will be explored in more depth in Chapter 6

Paul *et al.*'s (2006) research focused on eleven residential schools and identified that, although the situation had greatly improved compared to the environment identified by French (2010) and Hreinsdottir and Stefansdottir (2010), there were still concerns. There was a lack of guidance surrounding physical affection and no clear definition of what was 'acceptable', potentially placing workers in vulnerable and difficult positions. Some staff ignored the guidance as they felt that pupils, so frequently away from home, required physical affection (Paul *et al.*, 2006). The report identified poor practice rather than abuse, but in some cases there was a 'worrying use of restraint' (Paul *et al.*, 2006, p.110) which echoed the findings of French (2010). Paul *et al.* (2006) identified that higher staffing levels allowed the staff to be more responsive to children overall than in

older-style institutions. Disabled children were identified as more likely to experience care in a residential school and also permanent separation from their birth family. Being placed in residential schools/ institutional care resulted in more children with learning disabilities being cared for by multiple caregivers and ensuring less opportunity to develop a secure attachment with a primary caregiver. This implies in relation to Maslow's theory (1943) that children in such institutions were failing to have their 'love and belonging needs' met due to being separated from their families and difficulty building close relationships due to multiple care givers.

### **Attachment in Adult Relationships**

Bowlby (1979) suggested that insecurely attached infants would generate 'inner working models which represent others as emotionally unavailable, untrustworthy and rejecting of the self as unlovable and of low value' (Howe, 1995, p.82). Bowlby suggested this could stop individuals from seeking love and companionship, fearing they were 'unlovable', resulting in individuals who expected little within relationships and experienced relationships which were insecure and unfulfilling. Bowlby (1979) stated that such individuals became 'closely involved in others, but always in the role of giving care and never receiving it' (p. 139). He proposed that they attempt to resolve their issues from childhood by wanting to feel needed by a partner. Mattinson and Sinclair (1979) identified that such individuals would rather remain in a relationship than be alone as they feared loneliness. This type of relationship resonates with those depicted in research with women with learning disabilities by McCarthy (1999): women frequently experienced relationships with partners who were 'troubled' and experienced little emotional support in return. This suggests a possible link between the attachment formed within an institutional setting and poor relationships in adult lives.

Bowlby (1979) claimed that healthy adults look for suitable partners who can provide a 'secure base' to form a relationship. Hazan and Shaver (1987) linked the childhood attachment styles identified by Ainsworth *et al.* (1978) (secure, avoidant and anxious/ambivalent) to romantic relationships. Securely attached infants considered themselves worthy of respect (Jacobsen and Hoffman, 1997), avoidant attached adults considered themselves unlovable (Larose and Bernier, 2001) and anxious/ambivalent attached adults developed a negative self-image and used emotions to gain attention (Kobak *et al.*, 1993). This was comparable to Maslow's theory (1943) where individuals who had not met their 'safety and security needs' failed to develop feelings of self-respect or self-confidence, however unlike Ainsworth *et al.* (1978) and Hazan and Shaver (1987), Maslow had limited evidence to support his theory.



Feeney and Noller (1990) suggested that participants who were identified as securely attached experienced longer loving relationships. 'Secure' subjects were trusting in their relationships with high levels of self-confidence, however all their participants were first year university students and their confidence, and therefore results, may have been affected due to this major change in circumstances. Also, finding a long-term partner for first year students may be less of a priority than meeting new people, sharing new experiences and studying. Franz *et al.* (1991) followed up participants from Sears (1957) research which examined child-rearing practices thirty-six years later and demonstrated that loving relationships in childhood lead to stable, happy marriages and close friendships in adulthood. Franz *et al.* (1991) research warrants merit as it included a wide range of participants from a range of economic backgrounds and followed up the participants over a long timescale. The research, however, excluded single parents and children with disabilities so the application of findings to these groups is questionable. It was understandable that single parent families were less prevalent in 1951 than they are today (see Section 2.2) and would therefore be excluded. Research by Levitt (2006) examined the experiences of women without learning disabilities in 'successful' relationships, however the researcher did not define the term 'successful', leaving this open to interpretation. The participants in the study described their partners as 'more mature, more caring, and possessing unusually positive characteristics' (p. 457). The attributes described as desirable by the women resembled those of a caregiver with whom a secure attachment could be made. The research included women aged 27- 38 years. There was no data for women outside this age range who may have defined a 'successful' relationship differently based on their experiences. All participants were female, well-educated and practicing Christians and this influence was not discussed. It was also unclear what impact gender had: male participants in successful relationships may have defined their partners differently.

Attachment was linked to other aspects of romantic relationships, such as trust, which contribute to relationship success. In a comprehensive study with five forms of data collection, individuals with poor attachments were found to experience lower levels of trust within relationships and experience difficulty overcoming trust violations (Mikulincer, 1996). Trust was a desired quality in relationship (Mikulincer, 1996) and related to Sternberg's (1996) definition of intimacy. For securely attached participants, increased trust led to intimacy and the development of reciprocal relationships; for insecurely attached individuals trust related to security and control (Mikulincer, 1996). Anxious/ ambivalently attached individuals were less able to cope with threats to the relationship, based their perceptions of their partner and relationships on one relationship threatening event and were more likely to terminate the relationship

(Simpson *et al.*, 1999). However this research only included university students with no relationships being longer than 18 months. More established couples may have overcome the threat due to increased intimacy and trust which can develop as relationships mature. Maslow's (1943) theory professed that a lack of trust implied a person's 'safety and security needs' had not been met in childhood which would have allowed them to ascend the hierarchy and meet their 'love and belonging needs'.

A decrease in trust and intimacy can lead to infidelity. In a longitudinal study, Russell *et al.* (2013) connected attachment anxiety to infidelity, as individuals who felt their needs for intimacy were not being met sought an alternative partner to fulfil them and had less commitment to the relationship. Russell *et al.* (2013) emphasised the limitations of their study, in that the sample only included Caucasian participants and infidelity was reported more frequently in African-American and Hispanic populations (Allen *et al.*, 2005). Insecurely attached individuals had higher numbers of sexual partners (Bogaert and Sadava, 2002) and more casual than long term relationships (Hazan and Shaver, 1987). Péloquin *et al.* (2013) identified that individuals with low attachment anxiety were more likely to have sex to demonstrate how they valued their partner and to experience more sexual satisfaction than those with high attachment anxiety. Péloquin *et al.* (2013) had a varied sample, in respect of ages and occupations, however over 70% were women and gender difference was not explored as a possible variable. Impett and Peplau (2002) suggested that women with attachment anxiety were more prone to engage in unwanted sex to please a partner, possibly to either increase intimacy or in an attempt to prevent the partner leaving. Impett and Peplau's (2002) research only included women, making it unclear how typical was this behaviour for men.

In summary, attachment is a fundamental requirement in childhood in order to produce adults who are securely attached, able to form lasting attachments and experience love. Growing up in institutional care away from family leads to a possible reduction in one's ability to form secure attachments and the literature indicates that this is due to a lack of affection and individualised interaction with a primary caregiver. Research suggests that those with insecure attachments have poorer relationships as adults and an associated lack of trust, often remaining in unsatisfactory relationships for fear of being alone and unlovable or being able to secure a long-term, loving relationship. Attachment theory is linked to sexual behaviour; insecurely attached individuals have more partners and less commitment to relationships and also use sex as a way to increase intimacy and retain partners.

The ability to form a secure attachment provides a partial explanation for what makes a long term partnership successful. Love appears central to the formation and maintenance of long term relationships and it is when couples are unable to maintain their loving attachment that the relationship breaks down. Attachment theory considers love as fundamental to relationships as opposed to the security and social status relationships provide (Maslow, 1943). The key areas of tension and agreement between attachment theory and Maslow's theory in regards to relationships will be discussed in the next Section.

### **2.3.6 Maslow and Attachment Theory- Areas of Tension and Agreement**

After extensive research, Maslow's (1943) theory and attachment theory were considered to be the most relevant to my study and provided two competing approaches of human development which attributed different levels of significance to love and relationships, with clear areas of tension and agreement between them. Both share an understanding of the significance of childhood experiences in forming adult relationships and the important role that the primary care giver plays in the development of balanced individuals. Both theories believe that infants benefit from consistency and stability in order to feel safe and the role of the primary care givers is to negotiate danger. Both agree that abuse negatively impacts on the development of successful adult relationships.

Love's importance is the key area of tension between them. Attachment theory places the experience of 'being loved' in childhood as a fundamental requirement to experience healthy adult relationships (Bowlby, 1973). Maslow (1943) saw its importance as being part of a process to facilitate self-actualisation, to increase security and social status but not as a 'basic need'. As stated previously, Maslow's theory provides an explanation of the historical view of relationships with primary significance afforded to security and social status, whereas attachment theory considers love and intimacy to be fundamental. Attachment theory affords further weight to love by linking it to self-esteem, arguing that the more loved (securely attached) the person is, the higher self-esteem they have (Howe, 1995). This was in contrast to Maslow (1943) who linked self-esteem to status and recognition. This implies that the theories were based on different value systems.

A substantial difference between the two theories is that attachment theory is a theoretical explanation of relationships whereas Maslow's theory is a goal orientated

model of understanding with a clear practical use. Attachment theory was primarily concerned with how individuals grew in relationship with others, as the 'self' developed as part of a social context (Howe, 1995). Maslow's theory affords limited significance to relationships and is focussed on the individual's ascension of the hierarchy to achieve self-actualisation. Attachment theory is a relational model and discusses the individual in relation to an 'other' whereas Maslow's theory is more individualistic (Kenrick, 2010). This is evidenced in the goal of Maslow's theory being to self-actualise, whereas the implied driver of attachment theory is to develop healthy relationships with oneself and others. Attachment theory states how the development of personality is rooted within society and culture and how the self develops through managing the cultural world (Dunn, 1988). Maslow (1943) claimed culture was not as significant. In spite of 'superficial differences such as differences in style of hairdressing, clothes, taste in foods etc.' (p.381) people of different cultures share more similarities than differences. Maslow typically describes the self in isolation and devoid of culture, which could be considered a weakness as attachment theory possesses an additional layer of complexity that Maslow's theory lacks.

Attachment theory is rooted within empirical evidence (Bowlby, 1969, 1973 and 1980 and Ainsworth *et al.*, 1978) and my review of the literature demonstrates how attachment theory has been applied extensively in social work, psychology, counselling and education. Despite its widespread use and familiarity within the human sciences, there is limited empirical evidence to support Maslow's theory (Dietch, 1978). Maslow's theory has been predominantly applied to organisational/ business research (Soper *et al.*, 1995). Bowlby continued to develop his perspective based on research (Howe, 1995) but Maslow did not. Both theories have been criticised for only being applicable to individualist, as opposed to collective, cultures; attachment theory ignores societies with multiple caregivers (Hrdy, 2005) and Maslow's theory is not applicable to collective society due to his focus on the self and personal freedoms (Cianci and Gambrel, 2003). The review of the literature identified one article which directly compared the two theories, however this included minimal information relevant to my research. Table 2, based on my review of the literature, highlights the main areas of agreement and tension between the two theories.

**Table 2: Attachment Theory and Maslow's Theory of Human Motivation**

Areas of Agreement	
<ul style="list-style-type: none"> <li>• Childhood experiences are significant in forming adult personalities</li> <li>• Good parenting from primary care givers is important for developing balanced individuals</li> <li>• Inconsistent parenting makes children feel unsafe and affects development</li> <li>• Primary care givers are the key to safely negotiating danger</li> <li>• Abuse within childhood can significantly impact on relationships in adulthood</li> <li>• Relationships are important in enabling people to develop resilience</li> <li>• More applicable to individualist as opposed to collective cultures</li> <li>• Criticised by feminists for its approach to the role of women</li> <li>• Both universally known theories across the human sciences</li> </ul>	
Areas of Tension	
Maslow	Attachment Theory
Love is not a 'basic need'	Love is a fundamental 'basic need'
Love is a process to facilitate self-actualisation	Love is required to experience healthy adult relationships
Goal orientated theoretical model to reach self-actualisation	Theoretical explanation of relationships
Limited empirical research	Grounded within empirical research
Individualistic theory with limited reference to others	Relational model with a focus on 'another'
Applied predominantly to business management and motivation	Applied predominantly to social work, child development and psychology
Limited reference to societal and cultural influences	Heavy focus on societal and cultural influences
Personality development occurs throughout life	Personality development linked to childhood experiences
Focus on social status	Social status not considered important

Both theories will be explored in relation to my participants, however it was hypothesised that attachment theory had more validity in relation to the importance of love within relationships. This was due to the significance highlighted by various theories of love (Section 2.3.2), the emphasised need for intimacy (Section 2.3.3) and the weight attributed to secure attachments as a predictor of relationship success (Section 2.3.5). Attachment theory is grounded in empirical research and its development has included the social, historical and cultural influences outlined in

Section 2.2.

Section 2.4 examines the research for people with learning disabilities and relationships in conjunction with attachment theory and Maslow's theory.

## **2.4 People with Learning Disabilities and Intimate Relationships**

As we have seen, there is a significant body of research exploring what people without learning disabilities desire in a potential partner, but there is a deficiency in this area of research for people with a learning disability which my research now explores. The majority of research relating to relationships for people with a learning disability has focused predominantly on sexual relationships including issues of consent, sexual education and sexual abuse. The review of the literature identified that a significant portion of the research focuses on the challenges faced by individuals in relationships. The next Section presents a review of the literature on intimate relationships for adults with learning disabilities and identified the key challenges as:

- Historic Attitudes to People with Learning Disabilities

- The Law

- Staff and Professionals' Attitudes

- Environmental Challenges

- Physical Relationships and Abuse

- Experiences of relationships beyond a sexual relationship

### **2.4.1 Historic Attitudes to People with Learning Disabilities**

What is presented here is a brief overview with the subject explored in more depth later in the thesis (see in particular Chapter 6) where societal, political and historical influences upon participants will be examined.

By 1954 in the UK there were approximately 58,100 people with learning disabilities living in long-stay hospitals (Department of Health and Social Security, 1971). This remained the main form of care provision for this client group until the 1980s when the hospitals began to close and their inhabitants were resettled within the community. Learning disabilities hospitals segregated patients by gender, with minimal integration between the sexes, due to a fear of sexual relationships developing. At the end of the nineteenth century, the eugenics movement became increasingly influential in British politics (Brignell, 2010). This movement was based on Darwin's 'survival of the fittest' concept in animals (1859), evolution being seen as having occurred due to natural

selection where weak traits were eliminated in the evolutionary processes. Darwin's cousin, Galton (1869) first used the term 'eugenics' to apply the principle of selective breeding to humans. The eugenics movement's premise was that the physically, morally or mentally weak individuals could be removed from the human race if only physically, morally or mentally strong people procreated.

Due to the popularity of this movement there was an inherent fear that having a 'learning disability' was hereditary and a drive began to stop any procreation between people with learning disabilities (Howard and Handy, 2004). As discussed in Section 2.2, it was not uncommon for women with learning disabilities of child-bearing age to be forced into enter institutions to prevent them having an illegitimate child (Hreinsdottir *et al.*, 2006) and there were routine sterilisations to prevent pregnancy (Roy, 2010). As highlighted in Section 2.2 unwed motherhood was considered unacceptable until changes in society in the 1970s (Koffman, 2012). As late as 1975, women with learning disabilities could be sterilised involuntarily and parental consent was used if they were unable to provide consent, however there was evidence that not all 'consenting' women understood the implications of the procedure (Hreinsdottir *et al.*, 2006 and Roy, 2010). This was in contrast to the sexual freedom women without learning disabilities were experiencing as a result of the introduction of the contraceptive pill (see Section 2.2).

Within learning disability hospitals there was little opportunity for mixing between the sexes except in controlled environments and there was a lack of privacy in communal areas. Abraham *et al.* (2010) interviewed adults with disabilities who lived in such institutions in the late 1950 to the late 1970s about their experiences of segregation. When describing social occasions where sexes were able to mix they explained that they could 'dance together, round the nurses and then when the music finished the men went one side, the women the other' (p.95). Abraham *et al.*'s (2010) research only presented the views of a small number of individuals living in one institution, however their description of rigid control was congruent with other accounts from that period (Hreinsdottir *et al.*, 2006 and French 2010). This was in contrast to the relaxation of sexual attitudes, including an increased tolerance of sex before marriage and homosexuality, in this period for people without learning disabilities (as explored in Section 2.2.)

Society (including professionals) frequently perceived the sexuality of people with learning disabilities in two polarised ways, either as 'innocents' or 'sexual deviants', which determined how individuals were treated (Brown, 1994). Those who defined

people with learning disabilities as being 'sexual deviants' considered them oversexed or perverts and felt society needed protecting from them due to their inability to control their sexual urges. It was unclear how this impacted on the treatment they received in hospitals beyond rigid segregation. McCarthy (1999) explained how 'any signs of sexual interest or arousal were ignored, repressed or misunderstood' (p.53). Those who perceived people with learning disabilities as innocent considered them to be vulnerable, asexual and requiring protection from society. Professionals who saw people with learning disabilities as eternal children (Brown, 1994) thought they lacked sexual desire and treated them as infants. It can be argued that this attitude is still evident today. Terry and Campbell (2009) highlighted the controversial case of Ashley 'the pillow angel' who, at the request of her parents, was subjected to invasive medical treatments to prevent her from reaching sexual maturity, eliminate pain from menstruation and keep her a 'manageable' size so they could continue to care for her. Critics claimed this was against her human rights and a denial that she could become an adult with any sexual feelings. What was commonly absent was the appreciation that people with learning disabilities had the same need for love, intimacy and affection as the rest of the population. Within hospital settings this was not accepted, understood or encouraged and staff met only their 'basic needs' such as food and shelter; in relation to Maslow's theory (1943) they were ignoring their 'love and belonging needs'.

Public opinion thought that institutional care was the best option for people with learning disabilities until the publication of the 1957 report by the Royal Commission on *The Law relating to Mental Illness and Mental Deficiency* (the Percy Report). The report identified that a community-based approach to care for people with learning disabilities would be preferable to care within segregated hospitals (Barber, 2012). Wolfensberger (1972, 1983) developed the work of Howe and Nirje (1980) to form the principle of Normalisation. Normalisation was the belief that people with learning disabilities should lead a life as similar as possible to that of everyone else in society. The concept was originally developed in Scandinavia by Nirje (1980) and was simply defined as 'making available to mentally retarded people patterns of life and conditions of living which are as close as possible to regular circumstances and ways of life in society' (p. 33).

Wolfensberger's normalisation principle was more complex and revolutionary, with four main aims which were:

- The use of culturally valued means to enable people to lead culturally valued lives
- The use of normative means to provide life conditions which are at least as good as average citizens'



- The enhancement of the behaviour, appearance, experience and status of the devalued person
- The use of culturally normative means to support behaviour, appearance and status which are themselves culturally normative

(Adapted from Wolfensberger, 1980b, p8)

This principle drove the change in social care provision, the closure of the long stay institutions and attempts to re-integrate people with learning disabilities into society. The desire to close hospitals was also favoured by the public following a number of abuse cases within hospitals and issues regarding staffing, management and conditions being outlined in books such as *Put Away* (Morris, 1969). There were also specific inquiries into allegations of abuse and the horrific conditions people lived in such as the *Ely Hospital Report* (Department of Health and Social Security, 1969). The 1971 White Paper *Better Services for the Mentally Handicapped* advocated the closure of the long stay institutions and the government confirmed their commitment to improve services for this marginalised group.

The normalisation principle has been criticised by subsequent researchers such as Baxter *et al.* (1990) for not acknowledging the cultural and racial differences within this group. Chappell (1990) further criticised the fact that there was no consultation with people with learning disabilities to identify their views. However, in the early 1980s advocacy was still in its infancy. It was not common practice to consult with people with learning disabilities on topics that affected their lives. Other important issues such as a life reliant on benefits, living in poverty and being segregated from mainstream society in day services were not discussed within the normalisation literature (Chappell, 1992). Despite these criticisms, the principles and writings of people such as Wolfensberger drove the government and policy makers to significantly change how adults with learning disabilities were supported to lead independent lives. The progressive changes that occurred within the 1980s for people with learning disabilities were reflective of those which were occurring within other marginalised groups such as homosexuals. As described in Section 2.2, this was the era where negative stereotypes surrounding sexuality, disability and difference were being challenged.

Following the hospital closures, people with learning disabilities were placed into smaller community-based services and were expected to take part in mainstream society. The publication of *Valuing People* (DoH, 2001) outlined their rights to have increased opportunities, greater involvement within local communities and to make and maintain relationships with others. *Valuing People* (DoH, 2001) was also explicit in

identifying that these individuals had the same rights and responsibilities as other citizens. However, *Valuing People Now* (DoH, 2009) identified that almost a decade later, people with learning disabilities still had fewer relationships than their non-disabled peers due to the exclusion of people with learning disabilities from locations where they would meet potential partners such as at work.

#### **2.4.2 The Law**

The 1956 Sexual Offences Act made it illegal to have unlawful sexual relationships with a female defined as 'mentally defective' or whom the man 'knows to be an idiot or imbecile'. This resulted in any woman classed as 'mentally defective' being excluded from a sexual relationship regardless of whether she could consent or not, which today would be an infringement of her human rights (Human Rights Act, 1998). The 1956 Act made no reference to men defined as mentally defective or homosexual relationships, suggesting a fear of pregnancy. This remained in place until the Sexual Offences Act 2003. The language changed from 'mentally defective' to anyone suffering from a 'mental disorder', but the focus became their 'capacity', rather than their disorder. The Sexual Offences Act 2003 defined capacity as 'a person consents if he/she agrees by choice and has the freedom and capacity to make that choice'. It stated that they must understand the nature of the act and potential consequences such as pregnancy and sexually transmitted diseases. Due to individuals' vulnerability the provision of contraception would not protect them sufficiently if they did not have an understanding of the social and emotional consequences of having sexual intercourse. The changes to the Sexual Offences Act 2003 were significant as they made it an offence to have sexual intercourse with a person who lacked capacity rather than a woman defined as 'mentally defective'.

*Safeguarding Adults: a consultation on the review of the 'No Secrets' guidance* (DoH, 2009) highlighted the need to improve the safeguarding of vulnerable people in the community and although this was a positive step, there was a concern that these measures could be used to 'safeguard' people from relationships in which they are happy to participate but staff felt uncomfortable about. Therefore, it would be important that staff working with people with learning disabilities do not assume that the people they support lack capacity to have a relationship as this does not comply with the Mental Capacity Act 2005. Staff, however, must be clear that they have capacity to engage in a sexual act otherwise they would be in breach of the Sexual Offences Act 2003 as it is not possible to decide that, despite lacking capacity, it is in a person's 'best interests' to engage in a sexual relationship. Current guidance suggests that staff, when

concerned, should conduct an assessment of a person's understanding of sexual and personal relationships. In relation to Maslow's theory (1943), this places staff in a position of power, deciding whether a person's 'basic need' for sex could be fulfilled.

A landmark legal case was that of SK in 2008 (*Ealing LBC v (1) KS (2) LU (3) SK (by her litigation friend the Official Solicitor) (4) MHAS (5) SR* [2008] Fam Law 633), which demonstrated the complexities of an individual's capacity to consent in regards to relationships and the law. SK was an Asian woman with learning disabilities and mental health issues who was married at the insistence of her family on several occasions for financial gain or to allow a family member to gain access to UK citizenship. Her partners were abusive and violent. A judge ruled that she had the capacity to consent to sexual relationships on some occasions when her mental health was good. She, on occasions, understood the medical and emotional consequences of sex. The judge, however, felt she lacked a full understanding of marriage, the commitment it entailed, the ability to fulfil requirements such as sharing a domestic life together and being able to support each other. The judge ruled that the key components of a marriage were the commitment and support provided to a partner. This directly links back to the theories of love proposed by Rubin (1970) and Sternberg (1996). Both Rubin (1970) and Sternberg (1996) emphasised the requirement for partners to have the capacity to develop an intimate relationship, to have the ability to make a commitment to a partner and be able to put their needs first. This was felt beyond SK's comprehension. This demonstrated that even if a person was able to consent to sex, their ability to consent to marriage can be problematic in terms of having capacity to make such a long-term and complex commitment to another individual. Sex and intimacy were viewed as separate issues within the law and this ruling implied that sex was easier to understand than a complex concept such as intimacy. The judgement also reinforced Maslow's concept that sex and romantic love are distinct needs. Therefore the embodied reality of a person's learning disability, such as impaired cognitive functions, could limit their ability to understand complex concepts and meet the 'higher psychological needs' of Maslow's hierarchy such as intimate relationships.

### **2.4.3 Professional Attitudes**

A media campaign by the FPA (2008) 'It is My Right' centred on the rights of people with learning disabilities to have sex and relationships and stated that they were often denied the help to pursue sexual relationships. The campaign was launched because of a research survey conducted by the FPA that explored the views of nurses, operational directors, training consultants, senior managers, lecturers, day centre

officers, therapists and psychologists. The survey indicated that 94% of respondents thought barriers existed which prevented people with learning disabilities from having sex and relationships (Family Planning Association, 2008). The survey claimed that 38% of respondents felt society's attitude was the main barrier to forming relationships for people with learning disabilities. This demonstrated that the liberal sexual attitudes outlined in Section 2.2 had not been fully extended to people with learning disabilities, despite sexuality and personal relationships training being provided to both people and staff as early as the 1970s (Kempton and Kahn, 1991). Unfortunately there was no breakdown of the responses to the survey, so there was no indication as to whether respondents' professions affected their views. Professionals were polled and 60% claimed they were working in some way personally to challenge existing attitudes, but there was no further information on how they were doing this. A small number of quotes were provided to support the survey data and overall these were positive accounts. It would have been beneficial to see the responses of less positive professionals in order to provide more balance. The survey implied that people were not meeting their 'physiological need' for sex due to barriers posed by society.

When people with a learning disability live within an environment where they are supported by staff it must be acknowledged that, despite whatever practices are implemented to increase autonomy, staff still have a significant control over their lives. Brown (1994) highlighted how paid staffs' attitudes and values were more optimistic and open compared to that of the parents of people with a learning disability. Parents considered that it was the role of support services to protect their child from sex and, in general, felt there was little distinction between consensual or non-consensual sex (Brown, 1994). Brown's research was conducted over fifteen years ago so it may be that attitudes have become more progressive, however the FPA (2008) research suggested this was unlikely. Protection from abuse or exploitation can be considered as a positive function of the presence of support staff, however it could be just as abusive to people's civil liberties when this protection forms a possessive barrier preventing people with learning disabilities from engaging in intimate relationships. White and Barnitt's (2000) research was more positive, identifying that 'seven of the eight interviewees had some experience of an intimate relationship, the majority with the active support of or at least acceptance from family and carers' (p.274). As discussed in Section 2.2, since the 1960s there has been an increase in liberal attitudes in relation to relationships and sexuality for both people with and without learning disabilities. This change in attitude was reflected in support provider organisations beginning to offer training for the staff (Wolfensberger, 1972 and Kempton and Kahn, 1991) and having sexuality policies in place (McCarthy, 1999).

Despite this progression in liberal attitudes, Kelly *et al.* (2009) demonstrated that when people with learning disabilities were interviewed and asked to share their experiences some identified how they had been restricted from engaging in physical relationships by staff and how they held an understanding about what was 'not allowed'. The majority related stories of themselves or their friends being chastised by staff for being 'caught kissing' (Kelly *et al.*, 2009). They explained how people thought they could be expelled from their home for this type of behaviour and that their 'interactions with partners or potential partners were being monitored and felt that they were not trusted to have a relationship' (Kelly *et al.*, 2009, p. 313). Participants claimed they had no rights to challenge these restrictions and overall felt that staff did not listen to them in regards to relationships and that they had to ask permission to engage in relationships. As a result, participants in Kelly *et al.*'s (2009) research reverted back to the secrecy associated with institutions. Kelly *et al.*'s (2009) research took place in Ireland where their Sexual Offences Act 1993 states it is illegal to have sex with a person with a learning disability who cannot live an independent life (Government of Ireland, 1993). Ireland, unlike the UK, does not have the Mental Capacity Act 2005. Instead, the Irish Lunacy Act 1871 still dictates that some adults with learning disabilities are unable to make their own decisions such as the right to marry (Bane *et al.*, 2012). Ireland is also predominantly a Catholic country which traditionally does not support sex outside of marriage, a cultural aspect that was not explored in Kelly *et al.*'s (2009) research.

Participants with learning disabilities in Lesseliers' (1999) research explained how they felt professionals' attitudes had changed as some older participants claimed if they were younger now they would have a relationship but this was not acceptable at that time. This suggests that despite the advances in liberal attitudes towards sexuality for people with learning disabilities (see Section 2.2) some people were unable to forget the historic attitudes outlined in Section 2.4.1, which possibly inhibited them from engaging in relationships and attaining their 'love and belonging needs'. Lesseliers (1999) identified that even though participants had not directly been stopped from engaging in a physical relationship 'they were afraid that intimate or sexual behaviour would not be tolerated within the premises, consequently they did not dare mention their desires in this respect' (p.138). White and Barnitt's (2000) research was more positive, suggesting that the individuals were being supported by staff to progress in their relationships. Unlike other research (Kelly *et al.*, 2009 and Hollomotz, 2008), White and Barnitt (2000) identified that no participant claimed to have been discouraged from having a relationship and participants said they were given the advice they required from staff. Staff were not included in the research. White and

Barnitt (2000) identified that it was not possible to determine if staff responded this way because their behaviour was dictated by company policy or if they were naturally supportive. The sample size was also small so it was a possibility that this organisation was not typical of UK service providers for people with learning disabilities.

Rodgers' (2009) research is the only study included in the review which acknowledges the active role parents and carers often have in the development and maintenance of relationships. One parent explained how she supported her daughter to maintain relationships as her daughter often forgot to maintain contact due to her disability and had to be prompted to make telephone calls to friends. Parents, like staff, found themselves in conflict, wanting to help a child develop relationships and yet wanting them to remain in a safe, controlled environment.

In conclusion, a restrictive carer attitude appears to be linked to people with learning disabilities engaging in sexual relationships. There appeared to be no research that suggests that staff did not want people to have the other non-sexual aspects of a relationship such as love, friendship, companionship and intimacy. Interpreting Maslow's theory (1943), it could be implied that staff were apprehensive in supporting individuals to meet their 'physiological needs' (sex) but supported less controversial aspects of relationships such as intimate friendships (love and belonging needs). Staff were happy to support the companionate love proposed by Berscheid and Walster (1978) that includes tenderness and affection but lacks sexual passion. The reasons behind this were never fully explored, however the most common reason was for their 'protection' and this was especially relevant for parents. In relation to Maslow's theory, both staff and parents appeared in a position of conflict, of wanting to protect the person from abuse and ensuring their 'safety and security needs' were met but also wanting to enable a person to engage in a relationship to meet their 'love and belonging needs'. Females appeared most likely to be 'protected'. From the research included in this review, there was no discussion around fear of pregnancy. This was the main reason for segregation and sterilisation of women with learning disabilities pre 1970 (Howard and Handy, 2004) but it may not have been discussed in more recent literature as it would not be acceptable now for professionals to hold and express those views.

#### **2.4.4 Environmental Issues**

Staff, family and professional attitudes could have acted as a psychological barrier preventing people with learning disabilities from engaging in a relationship. However,

the review of the literature suggests that there were also environmental issues that acted as barriers to the development of relationships. For the purpose of this study, I have defined 'environmental issues' as issues that arose because of individuals' living conditions within a shared home environment with staff support.

Research by Lesseliers (1999) implied that the control exerted by 'paid staff' affected relationships, which was then compounded by individuals' living situations. Lesseliers (1999) stated that living in a group environment made it impossible to have a 'normal' relationship. However, what a 'normal' relationship is was not specifically defined. This suggests a 'predefined' judgment of what a relationship should be. Participants identified how living in a residential setting made it 'hard to make a space for relationships, especially intimate or loving ones' (Lesseliers, 1999, p.138), possibly suffering from a lack of privacy. Lesseliers' research was conducted in 1999 and since this time there has been a change in service provision moving from larger care homes to smaller supported living services. It is possible that people now have more privacy from staff and other residents.

An online search (conducted March 2013) identified that many care homes still only provided single rooms and the emphasis on providing a double-bedded room for couples mainly focused on older adults rather than those with learning disabilities. Hollomotz (2008) stated how some individuals only had single beds, making sharing impractical. My experience as a social care professional, both within my own organisation and my external contract work, has identified that many individuals still only have single beds. This can often be due to the size of the room, something outside of the support providers' control. The lack of challenge insinuates that the concept of people with learning disabilities requiring a double bed for a potential partner to share was not considered or acknowledged by staff. The provision of a single bed could be seen as an unacknowledged restriction by organisations regarding the development of sexual relationships by not providing couples with a comfortable environment for overnight visits. More could be done to challenge housing providers. The inability to have a double bed seems to be deemed acceptable for people with learning disabilities, suggesting they are different in some way from the wider population. It could be argued that a lack of privacy (security of personal space) constitutes an unmet 'safety and security need'.

Hollomotz (2008) implied that in the previous nine years there had been little improvement in levels of privacy for people who living properties with staff support. People with learning disabilities were described as remaining in a state of adolescence

due to their environment, forcing them to conduct relationships in secrecy. Hollomotz's (2008) research argued that the need for privacy in the development of the relationship not only related to sexual activity but the need to have intimate conversations which could be seen as fundamental to the development of a relationship. Participants described how staff had restricted members of the opposite sex from being in their bedrooms even if no sexual activity was taking place. Practical measures to inhibit privacy included having no locks on doors, sharing a room with another individual and staff not knocking prior to entry. Hollomotz's (2008) research was conducted with fifteen participants with a learning disability, however no information was supplied as to whether they all received support from the same provider organisation. If this information had been available it may have been possible to determine how widespread this issue was across a sample of support providers or whether it was just one organisation whose policies were restrictive. Having a key to the front door and bedroom of your home was significant to some people with learning disabilities (Fyson *et al.*, 2007) which could be interpreted as a symbol of authority. Fyson *et al.*'s (2007) research highlighted that in a section of 'supported living services' people were provided with keys but staff retained a 'master key' and used this to enter the property without authorisation from tenants. This was more typical in houses which had been de-registered from a care home. This implies that staff had not understood the aims of supported living and deregistration had not resulted in a change in attitude which encouraged autonomy. A lack of autonomy and recognition of their adult status could be considered a barrier to attaining their 'self-esteem needs' identified in Figure 1 A.

A lack of privacy was also evident outside of the home. Kelly *et al.* (2009) identified how some families and staff supported people on 'dates', which was unacceptable to some participants, e.g. one person explained how her brother accompanied her on dates to moderate her behaviour. What was absent from the research literature was the acknowledgement of the tension between individuals' needs and privacy: there may have been practical reasons as to why staff were present, such as supporting them to access transport. Most research surrounding this topic was written from a 'service user' perspective and therefore the level of disability people experienced was not discussed. However it may not have been possible for the person to participate in the 'date' or 'activity' without the support of staff and this was rarely acknowledged. This reflects the tension staff encounter in relation to Maslow's theory (1943) with staff presence required to meet the 'safety and security needs' of the people they supported, but this possibly limits individuals' ability to meet their 'love and belonging needs' due to a lack of privacy required for intimacy and affection.



The organisational and funding issues around the living situations for people with learning disabilities have been discussed in the literature, however the full extent of how problematic this could be has not been acknowledged by many researchers. The way services are commissioned has a major impact on their available options (Brown, 1994) and people funded by block contracts (where their service is commissioned and funded per property/group of properties) are not freely able to move home when they choose. Despite these issues, research by White and Barnitt (2000) has indicated that residential care homes can be seen as a way to meet potential partners for individuals with limited social circles. White and Barnitt (2000) uncovered that half of the participants in their study had met their current partner where they lived. White and Barnitt's (2000) research also highlighted what limited interactions people had with those who did not have a learning disability: all but two participants met their partner in a specialist location for people with learning disabilities. White and Barnitt (2000) is the only research which has explored this aspect of 'group living'. This could not be considered ideal but in instances where people had limited social circles this appeared a way to meet potential partners. Lesseliers (1999) acknowledged that 'separation due to re-housing seemed a recurring feature in the lives of many participants' (p. 138). This action suggests that staff/professionals undervalued these relationships and did not take them into consideration when making decisions regarding moves. This threatened individuals' 'safety and security needs' in terms of security of property; while they may not become homeless they will be forced from their home which raises concern as to whether organisations were adhering to the Mental Capacity Act 2005 which requires them to ask people for their consent before moving them. As more care homes become de-registered, a process which is happening routinely with local authorities providing 'toolkits' for providers, this will hopefully become less of an issue as people have tenancy rights in supported living services as opposed to a licence agreement in care homes which provide significantly fewer rights.

There were positive examples of support surrounding sex for people with learning disabilities. Family Mosaic Housing, one of London's largest care providers, appointed sex champions to teach staff that sex was a part of life for people with learning disabilities. Family Mosaic Housing did not feel they were meeting residents' needs and that sex was not discussed as staff were uncomfortable, which they attributed to a British attitude to sex in comparison to other more open European countries. This was a very progressive approach by Family Mosaic and it was unclear how many other organisations have similar programme/training for staff.

In summary, as with staff attitude, most of the justifications for depriving people of their

privacy have centred around protection based on the vulnerability of being an adult with a learning disability. Research has also demonstrated that there were elements of practice from organisations which could be deemed abusive, such as having restrictive policies in place around visitors and the way in which decisions were made to move people from their home. Nevertheless, some organisations are working hard to improve privacy and the support provided around sex and intimate relationships.

#### **2.4.5 Physical Relationships and Abuse**

Research that has explored the relationships of people with a learning disability mostly focuses on the sexual element of the relationship and abuse people may have experienced. A study by Lesseliers (1999) explored how people with disabilities perceived relationships and sexuality. Overall, no participant experienced a warm and tender relationship, and sexual contact was not enjoyed. A minority of couples in long-lasting relationships were able to obtain pleasure, however the reasons behind this success were not explored. The sample consisted of participants who lived in supported accommodation housing of between 40-60 people resulting in a lack of privacy. If the research had been conducted in smaller service settings the results may have been different due to the possible increase in privacy and potential to engage more in sexual relationships.

McCarthy (1999) described the relationships of British women with learning disabilities as frequently being abusive and themes emerged in her research which painted a negative view of the sexual lives of women with learning disabilities. She identified a lack of sexual agency among the women. Women did not decide themselves about whether or not to engage in sex or the type of sex in which they engaged and women often engaged in anal and vaginal sex. Although 'kissing and cuddling were preferred by one third of the women' (McCarthy, 1999, p.147), this was lacking in the relationships. This implies that their 'safety and security needs' were not being met and that they were possibly surrendering them in an attempt to fulfill their 'love and belonging needs'. This suggests that their desire for love overrode a 'basic need' to be safe. The relationships appeared to only be experienced on a physical level and the women appeared 'psychologically disengaged' when physically intimate. This reflects Impett and Peplau's (2002) finding that women with attachment anxiety had unwanted sex in the hope of maintaining the relationship and increasing intimacy and suggests that McCarthy's participants may have had issues surrounding attachment. There were romantic feelings from the women towards the men as half the women in the study said they had sex because they loved or liked their partner. This indicates, as argued by

attachment theory, that love/intimacy is a 'basic need' rather than sex as stated by Maslow (1943). The research by McCarthy (1999) only explored the views of women, which was understandable as the research was conducted based on a feminist methodology. However, it would have been of value to understand how the men in these relationships perceived the female participants and their sexual experiences. The participants were women in their thirties to fifties with experience of institutional living either in a group home or in a long stay institution. It did not include the views of younger women or those with no experience of institutional living who may have had different experiences. Overall, the outcomes for the participants in most of the research in this area could be categorised as negative and there is little description of success within relationships. This further highlights the tension experienced by staff between protecting peoples' 'safety and security needs' alongside supporting their right to engage in relationships (if they have the capacity).

Berscheid and Walster (1978) defined love as either passionate or companionate love, but participants in both Lesseliers' (1999) and McCarthy's (1999) research indicated that they experienced neither. Participants did not enjoy the sexual aspect of their relationships and therefore did not experience an 'Eros' love style as identified by Lee (1973), which focused on sexual desire (Section 2.2.1). Their relationships lacked the intimacy and commitment required for a loving relationship as conceptualised by Rubin (1970) and Sternberg (1996). Female participants in McCarthy's (1999) research were not experiencing any of the love types identified by Lee (1973). Storge (companionate, friendship-based love) and Agape (selfless love, putting the other before oneself) were most absent. McCarthy's participants' need to 'be loved' appeared of greater significance than their physical or emotional safety, which contradicted Maslow's theory (1943). However, this may reflect their possible lesser ability to evaluate risks.

#### **2.4.6 Experience of relationships beyond a sexual relationship**

There is minimal research which has explored the experience of being in a relationship which does not focus on the sexual element of a relationship for people with a learning disability. Two of the most in-depth pieces of research which focus on the non-sexual elements of relationships for people with learning disabilities were conducted in the 1970s by Mattinson (1970) and Craft and Craft (1979). Both were extremely detailed and involved the interviewing of a number of married couples with learning disabilities over an extended period of time so, despite their age, were considered valuable and relevant to this research.

Mattinson's (1970) research involved thirty six married couples who had previously lived in a learning disability hospital and had moved to live independently in the community. The aim of this research was to discover how viable the relationships were. Mattinson (1970) explored the characteristics of the relationships and established that participants felt they were lucky to have found someone. The participants also recognised their need for each other and 'recognised their intellectual impairments and knew this would increase their chances of coping outside' (p.131). There are now more support services available to assist people with learning disabilities which may make this point less significant. This also provides evidence to support Maslow historical view of marriage's ability to increase security with couples possibly considering themselves to be stronger by pooling their property and finances.

All participants experienced poverty and had 'low expectations in life' (Mattinson, 1970, p.201). They were frank about their disabilities and believed in themselves as a couple. Mattinson did not have definitive proof but she felt that this belief was more important to participants than the sexual aspect of the relationship. Mattinson claimed there was a real investment in the marriage: participants had limited relationships outside of this, with 72% of participants having no friends outside the marriage which appeared to make the emphasis on marriage even stronger. This is still an issue today. Emerson and Hatton (2008) identified that people with learning disabilities are less likely than people without learning disabilities to have friends. Mattinson (1970) argued that the participants did not have a deep personal relationship with a focus on 'feeling and sharing as so much effort went into proving themselves in the community' (p.133). This point may have been a result of the research aim which was to determine how successful the relationships were. This may have affected how participants presented themselves and their story in interviews and focused more on their skills and capabilities. The love style was most comparable to Pragma (Lee, 1973), being rational and realistic and focused on collaborating with their partner to reach a common goal, which in the case of Mattinson's (1970) participants entailed coping outside of a hospital setting.

Craft and Craft's (1979) research had a similar aim, which was to see how couples 'fared' in married life, how much support they needed and how they coped with children. They interviewed forty one married couples, all defined as having one partner who was 'handicapped' and had experienced specialised care. Eleven partners did not have learning disabilities but most had some other form of disability such as physical disability, mental health or behavioural issues. Craft and Craft (1979) identified that participants came from 'unhappy homes' (this was not explicitly defined) or institutions

and they highly valued marriage. Marriage was seen to 'improve life, reduce loneliness and be of great value' (p.53). The relationships presented again reflected Lee's (1973) love style 'Pragma': participants supported each other and viewed love as a 'useful relationship' with practical benefits. What was not known is if this definition in this context differs from the wider population's views on marriage. Craft and Craft (1979) established that like Mattinson (1970), participants were poor and lived in unsatisfactory conditions.

What appears surprising in both Craft and Craft (1979) and Mattinson's (1970) research is how many people with learning disabilities they managed to locate who had lived in institutional care and were married and this did not even include those who were in relationships but unmarried. There appears to have been a higher level of marriages than currently found which reflects patterns within the general UK population. The number of married couples has been decreasing, declining by 457,000 between 1996 and 2012 (Office for National Statistics, 2012) and marriage rates have been falling since the 1970s. Couples in both Mattinson's (1970) and Craft and Craft's (1979) research appear to reflect Maslow's (1943) historical view of relationships, with limited significance attributed to love and primary significance afforded to social status providing a means of meeting their 'safety and security needs'. I believe their responses may have been influenced by the research aim 'to determine how they coped in society as a married couple'. Marriage was highly valued in both studies as it allowed couples to hold the social valued role of husband or wife and sometimes parents. According to Maslow (1943) attaining these roles may have assisted them to reach the penultimate layer of the hierarchy 'self-esteem needs'.

In a more recent experience of people with learning disabilities in relationships, Kelly *et al.* (2009) identified that most participants who were not in a relationship desired to be in one, suggesting that, like Craft and Craft (1979) and Mattinson (1970), relationships are highly valued. 'For the majority, relationships were seen in a very positive light and as a source of support and companionship' (Kelly *et al.*, 2009, p.312). This study also provides further exemplification of Lee's (1973) 'Pragma', with participants engaging in relationships that support each other. One participant stressed how romance was important and how she liked to be bought gifts by a partner. There did not appear to be any indication of this woman having an 'Eros' love style driven by passion and sexual desire (Lee, 1973) but instead showed how important it was for her to feel wanted and desired by a partner. This type of information was lacking in the research literature: there is limited research which identifies what people with learning disabilities value in a relationship. Male participants in Kelly *et al.* (2009) identified how appearance was

important in a potential partner, in particular 'slim and sexy blondes' (p.312). Females appeared less focused on looks and this was consistent with the findings of the typology when looking at what people without a learning disability look for in a potential partner (see Appendix 1).

All participants in Mattinson's (1970), Craft and Craft's (1979) and Kelly *et al's* (2009) research experienced relationships they highly valued. A high proportion of participants expressed a love which was representative of Lee's (1973) Pragma love style. Relationships focused on practically supporting each other to achieve the common goal of succeeding in life and providing companionship. Romantic and sexual elements were not explicitly stated as being important but this did not mean that the love expressed by participants was not 'good' or 'real'. Participants appeared to place significant trust and value on their relationships. No participant in any of the research included in the literature review described an 'Eros' love style (Lee, 1976) driven by passion and sexual desire. This is perhaps reflective of the perception within society regarding sexuality for people with learning disabilities, considering them as 'deviants or innocents' (Brown, 1994). This emphasises how the view of sex as a basic 'physiological need', as defined by Maslow (1943), is not universal. People with learning disabilities have possibly repressed their sexuality due to conditioning from society and therefore do not necessarily consider sex to be important or desired, or may not feel able to express such 'taboo' feelings to the researcher. The desire for love and intimacy indicate that 'love and belonging needs' as defined by Maslow (1943) were more important than sex.

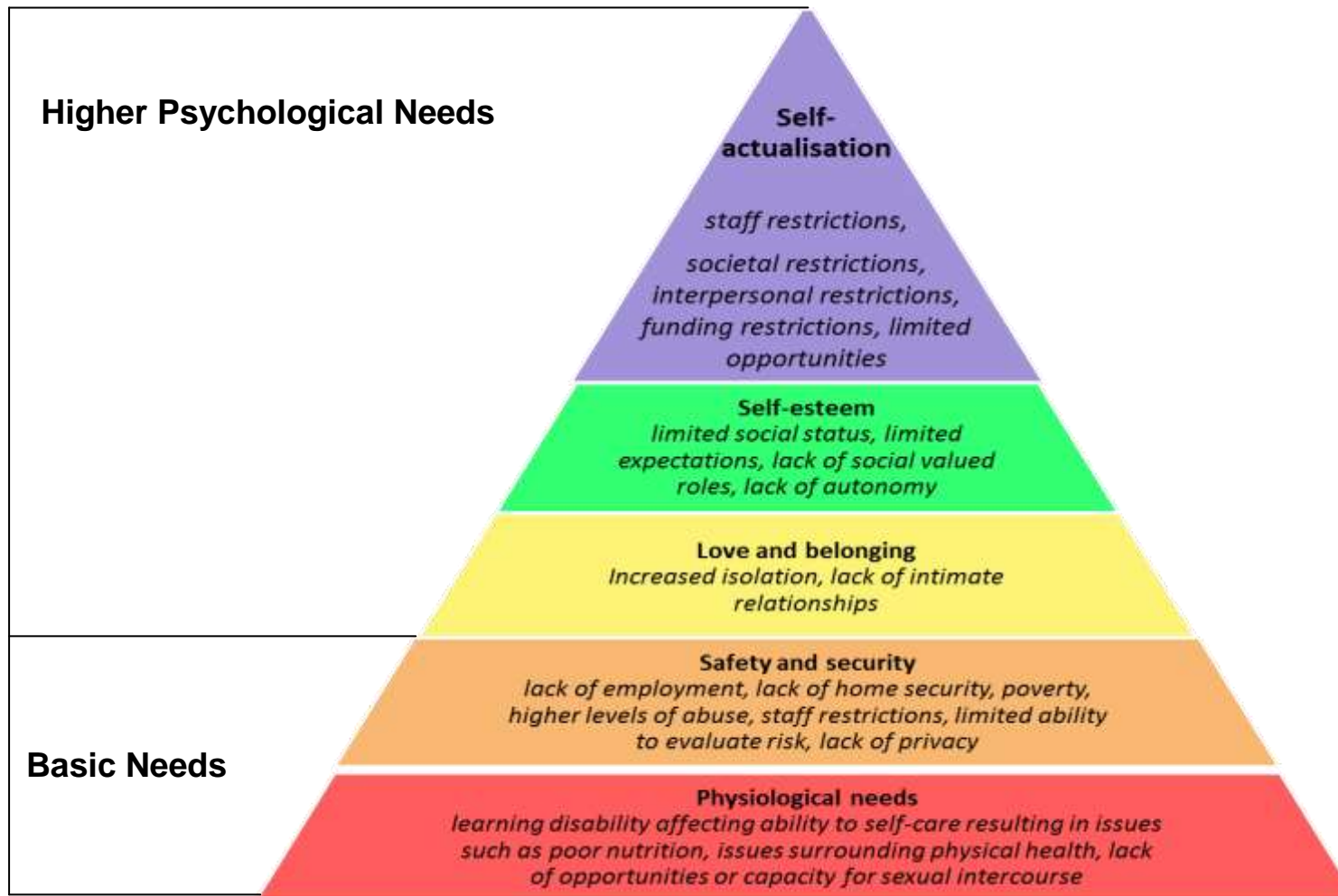
In summary, as explored in Section 2.2, post the 1960s there have been significant advances in society and culture in relation to sexuality and relationships. This has also resulted in more liberal attitudes towards people with learning disabilities and relationships. However, staff retained a position of power and responsibility in determining whether peoples' 'basic and psychological needs' were met. There appeared to be a consensus within the literature that most staff wanted the people they supported to have intimacy and friendships but sex appeared to remain controversial, possibly due to an inability to relinquish the historical attitudes outlined in 2.4.1. Most support provider organisations appeared to advocate, in theory, the attainment of 'love and belonging needs' to form a loving attachment. The review emphasised the tension experienced by staff, retaining the role of the primary caregiver to keep people safe. However, if staff protection was too prohibitive this had a negative impact on peoples' ability to form a relationship with a partner. There was no evidence to suggest that people with learning disabilities had achieved the higher levels of Maslow's hierarchy

such as 'self-esteem needs' in relationships.

Figure 1B presented below is a revised model of Maslow's traditional hierarchy, summarising the challenges evident from the literature for people with learning disabilities achieving the highest 'goal' of Maslow's theory.

The research relating to people with learning disabilities provided conflicting information concerning the importance of love within relationships. There was evidence to support Maslow's (1943) historical view of marriage as a means to increase security and social status (Mattinson, 1970 and Craft and Craft, 1979), however as discussed in Section 2.2, societies' attitudes to marriage have changed and this view was not as prevalent in more recent research (Kelly *et al.*, 2009). There was contrasting evidence to support the position of attachment theory, that love is most important in relationships (McCarthy, 1999 and Kelly *et al.*, 2009). McCarthy's (1999) research suggested that individuals were possibly willing to forfeit their safety to attain love, demonstrating its significance.

Figure 1B: Revised Hierarchy of Needs - Reflecting the challenges faced by people with learning disabilities as reflected in the literature





## 2.5 Research Questions

The overall review of the literature showed that loving, exclusive relationships were characterised in a variety of ways. Table 3 presents the different definitions across theories of what 'love' means within a relationship, demonstrating the similarity between various theories and researchers: almost all highlighted the need for some form of emotional and physical closeness and commitment.

**Table 3: Essential Characteristics of an Exclusive Relationship**

Researcher	Different permutations of 'what love is'
Maslow (1943/1954)	<ul style="list-style-type: none"> <li>• D love – Selfish and possessive</li> <li>• B love – Equal, unselfish and giving</li> <li>• Limited significance attached to love; primary significance attached to security and social status associated with relationships</li> </ul>
Rubin (1970)	<ul style="list-style-type: none"> <li>• Attachment – the desire to be close</li> <li>• Caring – putting other's needs first</li> <li>• Intimacy – including exclusivity in the relationship</li> </ul>
Sternberg (1996)	<ul style="list-style-type: none"> <li>• Intimacy</li> <li>• Passion</li> <li>• Decision/commitment</li> </ul>
Holt <i>et al.</i> (2009)	Intimacy – broken down into: <ul style="list-style-type: none"> <li>• Intellectual intimacy – shared goals/ problem solving</li> <li>• Physical intimacy – sexual relationship</li> <li>• Emotional intimacy – Accessibility, non-possessiveness/ commitment to the relationship</li> </ul>
Graham (2011) and Berscheid and Walster (1978)	<ul style="list-style-type: none"> <li>• Passion and sexual relationship</li> <li>• Compassion (similar to putting other's needs first)</li> <li>• Tenderness and affection</li> </ul>
Lee (1973)	<ul style="list-style-type: none"> <li>• Eros (passion/sexual)</li> <li>• Ludus (love as a game)</li> <li>• Storge (compassion)</li> <li>• Pragma (logical)</li> <li>• Mania (obsessive)</li> <li>• Agape (similar to putting other's need first)</li> </ul>
Typology highly valued traits	<ul style="list-style-type: none"> <li>• Kindness</li> <li>• Consideration – similar to Rubin's (1970) putting others first, Graham's (2011) compassion and Lee's (1973) Storge</li> <li>• Emotional bond – similar to Rubin's (1970) closeness and intimacy and Sternberg's commitment</li> </ul>
The legal case of SK	<ul style="list-style-type: none"> <li>• Marriage requires a long-term and complex commitment</li> </ul>

The review of the literature surrounding people with learning disabilities identified that people valued companionship and support and this appeared to be most significant for individuals who were living in poor conditions and in poverty. People experienced various challenges in their relationships, such as the prejudices of professionals and society, issues relating to shared housing and staff attitude, legal issues and issues of consent. Most research focused on the sexual element of the relationship and its inherent issues. The review did establish that little was known about partner selection for people with learning disabilities and my research aimed to address this and it was decided to focus on the intimate heterosexual relationships of adults with learning disabilities following the review of the literature. My two research questions were:

- What do people with learning disabilities look for in a potential partner?
- How do their prior experiences affect their choices and influence the relationships they experience?

Chapter 2 explored the research literature relating to partner selection for both adults with and without learning disabilities, identifying a gap in the literature which I intend to address. Chapter 3 explains how I undertook the research including the methodology, method, and a discussion of the key ethical issues within the research.

## Chapter 3- Epistemology, Methodology and Methods

### 3.1 Introduction

The literature review revealed that no research had been conducted which examined what people with learning disabilities desired in a potential partner or how their choices influence the relationships they experience. The review identified a limited amount of research that had explored the experiences of people with learning disabilities from their own perspective. The aim of my research was to explore what people with learning disabilities look for in a potential partner and to understand how their prior experiences affect their choices and influence the relationships they experience. The role of Chapter 3 is to explain how the research was designed to answer this question and why it was conducted in this way, discussing the other options that were available and why they were excluded. I aim to give a transparent, reflective account of the research in line with my chosen methodology and ontological and epistemological perspectives.

There are eight sub-Sections within this Chapter: the first, 'epistemological and theoretical understanding' (3.2) examines the two main epistemological and theoretical standpoints and demonstrates why my research is situated within the constructivist position. The next Section (3.3) explores the different methodological and phenomenological perspectives that were considered applicable for the research. Section 3.4 is a reflection on my discarded methodology, Interpretive Phenomenological Analysis (IPA), and this was pivotal as it explains why this was considered unsuitable and why Van Manen's hermeneutic phenomenology was selected as the methodology instead. Section 3.5 introduces Van Manen's methodology and explains why it was relevant to this research. The following Section focuses on the method (3.6), how and why the research was conducted in this way and the methodological issues encountered in the planning process. The Section on ethical issues (3.7) is important due to the vulnerability of the participants and includes a detailed account explaining how this issue was addressed. The final Section (3.8) concludes with a description of how I applied Van Manen's methodology of hermeneutic phenomenological reflection to the data collected in the interviews in order to form my interpretations.

### 3.2 Epistemological and Theoretical Understanding

The aim of this Section is to define and explain how my ontological and epistemological standpoints linked together to work congruently in underpinning my research. Two theoretical and epistemological perspectives underpin the course of research within the social sciences: naturalism (also defined as positivism or empiricism) and constructivism (also defined as interpretive approaches). The fundamental difference between these two perspectives is how they define 'truth' and 'knowledge'. Naturalistic researchers believe in an objective truth, that human experiences and behaviours can be objectively tested and measured and can exist independently from the researcher (Moses and Knutsen, 2007). This approach typically employs methods which can be quantified, such as controlled experiments and observations, and then use the results to make generalisations to the wider population. Naturalist researchers hold an underlying philosophical belief that patterns in nature create a 'unitary, knowable, objective reality' (McLeod, 2001, p.6). In contrast to the naturalists, constructivists attribute these patterns to the influence of individuals and their experiences as well as the influence of society and culture. Due to this individually constructed world view, constructivists believed there is no known objective reality (McLeod, 2001). Constructivist researchers did not 'objectively test' to understand a phenomenon, but instead explore how it has been constructed by examining how it has been shaped by society, memories, rituals, culture and individuals, while acknowledging that there are variables outside the researcher's control, such as the influence of gender, age, race, culture and language (McLeod, 2001).

I define myself as a constructivist researcher and agree with the concepts outlined relating to this approach in the above paragraph. This current research was based on individuals' subjective understanding of their relationships: it was not seeking to uncover a 'true account' of the relationships of people with a learning disability or to generalise the findings to other people with a learning disability or the wider population. I was interested in understanding what the experience of being in a relationship means to people with a learning disability and what influences the experiences they have. I believe that each individual experiences life in a way which is unique to them and this is something which should be valued and can deepen the understanding of a phenomenon. This recognition of human influence has often been neglected within the naturalistic tradition (Moses and Knutsen, 2007) and often seen as a bias which is the greatest threat to reliability and validity of data (Parahoo, 1997). Constructivist research has been criticised for being too subjective, (Armour *et al.* 2009) as the researcher utilises their own understanding to interpret the phenomenon. Constructivist

researchers such as Mehra (2002) have reinforced the value of the researcher's views, beliefs and experiences within the analysis, as long as these are fully explored and examined before the interpretation begins. I was aware that I held my own views and experiences on this topic, which has undoubtedly influenced my interpretations. This potential for bias is explored in more detail within Section 3.6.

While I appreciate and respect the merits of the positivist approach to investigating research areas where the subjects of the investigation do not have their own thoughts, feelings and experiences (like chemistry), the methods employed by naturalistic researchers would have been unsuitable for this research. Conducting experiments which manipulated some variable within them as is the case with naturalistic research methods would not have allowed as much opportunity to gain a realistic understanding of participants' relationships and probably been considered unethical. Other naturalistic methods such as observation were considered, but this would have also been unethical (and impractical) to observe couples in their natural environment. It would have been intrusive and particularly unethical to observe more intimate aspects of the relationship such as physical affection which could be discussed in interview. Naturalistic approaches appeared to be more 'researcher-led', whereas constructivist approaches such as interviews allow the participants more control over the research process. People with learning disabilities have a history within research and society of oppression and control (Walmsley and Johnson, 2003) so it was important to select a methodology which gave them some element of control within the process. While the participants did not have input in the design, analysis or writing of the research, they were able to control the interview to some extent, choosing what they shared and what they kept private.

It was clear that this research is rooted within the constructivist tradition and to produce a detailed account of the different methodologies within the naturalistic tradition and their inherent merits and disadvantages would be less beneficial. Therefore, the focus of my methodology Chapter is on the qualitative methodologies of the constructivist position.

### **3.3 Methodology and Phenomenological Perspectives**

The aims and objectives of this study are to explore what people with learning disabilities look for in a potential partner and understand how their prior experiences affect their choices and influence the relationships they experience. This included an understanding of their thoughts and feelings about their current relationship, including

their reflections on their partner and their hopes and aspirations for the future; their personal history including an understanding of their family relationships and social circles and previous partner experiences. Therefore I required a methodological approach which included the collection of detailed narrative accounts from individuals that would allow their experiences to emerge in their own words. Grounded Theory was considered as a possible methodology, but the aim of building a theory-based participants' narrative (Glaser and Strauss, 1967) was not applicable for my research. I did not intend to build a theory of relationships to apply to the learning disability population. I was interested in exploring the experiences of individuals within relationships.

The research was fundamentally about understanding experiences from people's perspectives. This is congruent with the primary aim of phenomenology which is to understand experience from the point of view of the person experiencing the phenomenon (Moran, 2000). This approach felt immediately congruent to me as a researcher, I felt an instant connection to its aims and values and considered them the most applicable to my research. Phenomenology was therefore selected as the most appropriate methodology to fit the aims of the research. A review of the main phenomenological positions was conducted to determine which one was most appropriate for this research.

Modern phenomenology is thought to have been established by Husserl in the early 1900s. He used the Ancient Greeks' notion of 'speaking manifesting truth' (Moran, 2000) to develop a methodology of philosophical enquiry which he termed 'as transcendental' or 'descriptive' phenomenology. This method of philosophical enquiry intended to understand the 'essential features' of an experience. The transcendental element suggested that these features would 'transcend' individual circumstances (how they appeared in the consciousness of others), which might illuminate an experience for others. Husserl spoke of a 'Lebenswelt' (life world) which he defined as the world as 'concretely lived'. He argued that phenomena were grounded within this but hidden by humans' 'natural attitude', which was based on preconceptions and understandings of the world. The central theme in transcendental phenomenology was not to use this experience to further our understanding but to see experience as an obstacle to move beyond. Husserl argued that it was this 'natural attitude' which obscured our ability to see things 'for themselves' (their essence). He advocated the use of bracketing, to silence our 'natural attitude' and see each thing in its 'own right' (Moran, 2000). This was done via Transcendental Phenomenological Induction. Husserl advocated that this was possible by giving a complete textual description of its essential features and

meaning. This continual questioning assisted in stripping back the multifaceted elements of a phenomenon until the essential features (essence) of an experience were revealed.

Husserl's methodology was considered for my research but was eventually rejected as it did not appear fully congruent with elements of my constructivist ontological perspective. The view that our preconceptions and understandings of the world, our unique experiences, were something to 'move beyond' in fully understanding a phenomenon did not feel correct. Without individuals seeing the world in context it seems impossible to understand a phenomenon, as everything is relative to the individual and their experiences. Also I do not believe it is ever possible to 'bracket', as I believe that experiences influence unconsciously, thus his concept felt to me too abstract to be applied in reality.

Research of the phenomenological literature confirmed that I held a similar view to Heidegger in relation to the role of lived experience. Heidegger challenged Husserl for being too abstract and theoretical (Moran, 2000), professing that phenomenon must be seen and understood in a cultural and social context. He developed his own phenomenological methodology, existential phenomenology. Existential phenomenologists viewed humans as meaning-making machines, striving to make sense of phenomena based on our own experiences and their historical meanings. In *'Being in Time'*, Heidegger (1978) discussed how pre-understanding could distort what is heard, resulting in what he defined as a 'vague understanding of being'. Rather than being a hindrance, this was described as necessary to enable further questioning (Heidegger, 1978). Heidegger argued this understanding formed the basis of hermeneutic enquiry, the questioning that drives the 'hermeneutic circle' (Heidegger, 1978). The term 'circle' related to the backwards and forward questioning that takes place, enabling the researcher to 'shed light' on phenomena to increase understanding. This was not defined as a linear process: the answers produced lead to further questioning and the circle continues. Heidegger claimed that this continual process of reflection generates new understandings.

Heidegger suggested that when developing a 'question for enquiry' (research question) this pre-understanding is central and that the question must originate from some known context. Without a pre-understanding there would be no question. My research questions were based in my pre-understandings and experiences of a professional working within the field of social care, coming directly from my experience of knowing adults with learning disabilities, including those who were in relationships and those

seeking them. Without this pre-understanding it would have been unlikely that I would have developed the same research question as they arose from my own experiences or have had the skills to undertake research interviews with this client group due to its inherent complexities.

Ontologically, Heidegger and I shared an understanding that research methodologies need to recognise and value past experiences and understandings. The experiences and understandings need to be viewed as central to the research process, guiding the researcher to develop the research question and providing the starting point for the questioning of the phenomenon, driving the hermeneutic circle of constant reflection to produce a new understanding. Heidegger's approach was considered as a possible methodology for my research, but was not selected as the philosophical language and concepts in his written work '*Being in Time*' (Heidegger, 1978) did not resonate with me as a student or researcher from the school of psychology and there appeared to be a lack of clear information on how to conduct research using this methodology. However, it was clear that the methodology used in my research would be rooted in Heidegger's concepts as opposed to Husserl's, valuing and using our past experiences to understand a phenomenon.

### **3.4 Interpretive Phenomenological Analysis - the discarded methodology**

Since it was clear that this research required a phenomenological based methodology, I spent considerable time researching the different proven forms of modern phenomenology and phenomenological methodologies which were not based purely within philosophy. I thought that the language used within them would be more familiar and they would be more readily applicable to my research. Initially the chosen methodology was Interpretive Phenomenological Analysis (IPA). Table 4 highlights the attractions of IPA versus the reasons to reject it as a methodology.

Although IPA met various criteria, there were many areas where it felt incongruent with the aims and the nature of the research. Ultimately, although it was a difficult decision to reject IPA, it would not have been appropriate to continue with this methodology and a better alternative, Max Van Manen's hermeneutic phenomenology, was found within an existential phenomenological perspective.



**Table 4: IPA – Attractions and Reasons to Reject**

Attractions of IPA	Reasons to Reject IPA
<ul style="list-style-type: none"> <li>• The literature provided clear instructions on how to conduct IPA research which was appealing to me as a novice phenomenological researcher</li> <li>• IPA used familiar language from my psychological background such as ‘cognitions’.</li> <li>• The aim of my research appeared congruent with this methodology, as IPA focuses on ‘questions of considerable importance’</li> </ul>	<ul style="list-style-type: none"> <li>• Written IPA research did not fully convey the authentic human experience, due to the ‘scientific’ underpinnings and the language of this approach.</li> <li>• The psychological language and increased engagement with the psychological literature did not feel appropriate as I was not conducting a piece of psychological research</li> <li>• IPA focuses on cognitions and it would be difficult to use IPA as a methodology without discussing how the cognitions of this group may be different to adults without a learning disability, which is not congruent with the nature of this research. It felt inappropriate when working with those whose mental capabilities were impaired and their cognitive ability was irrelevant in this context.</li> </ul>

### 3.5 Hermeneutic Phenomenology - Max Van Manen

Max Van Manen (1990) and his definition of ‘Hermeneutic Phenomenology’ in *Researching Lived Experience* reflected the interpretive methodology of Heidegger (1978). This Section will explain why, after careful discussion and deliberation, Van Manen’s methodology was chosen for the research.

Van Manen valued the human element in research, ensuring that an individual was reflected in context. This was important to me considering my ontological and epistemological position. Van Manen, like Heidegger, claimed context was central in understanding a phenomena as it is always ‘a project of someone, a real person who in the context of particular individual, social and historical life circumstances sets out to make sense of a certain aspect of human existence’ (p.31). Van Manen (1990) shared a common goal with other phenomenological methodologies in that he intended to ‘transform lived experience into a textual expression of its essence’ (p.36), meaning that the text produced by the researcher reflected the experience of the individual and

that the reader was able to 're-live the experience' through the interpretation of the text. His methodology was used by me to enable readers without a learning disability to 'live the experience' of how participants with a learning disability experience their relationships through their narrative accounts. The difference between van Manen and other phenomenologists appeared to be the 'everyday' language of his approach, in particular the accessibility of the key text which outlined his methodology *Researching Lived Experience* (1990). Van Manen was an educationalist, not a philosopher, which could be why his methodology appeared more readily applicable to my research as teaching traditionally has more of a practical application than philosophy.

Van Manen (1990) considered writing as 'the methodology' in his research. This was supported by Barthes who said 'Research is the work of writing - it is its very essence' (1986, p.316). A good phenomenological description was one which 'reawakens our basic experience of a phenomenon it describes' (Van Manen, 1990, p.122). Van Manen's Hermeneutic Phenomenology suggests that there is no correct interpretation of an experience. Even if the interpretation of the account itself is incorrect, it is still valuable. Hermeneutic Phenomenology was less focused on 'facts' but on what an experience means to someone. According to Van Manen, the process of establishing what an experience means to an individual is achieved via 'systematic' questioning (like the hermeneutic circle described by Heidegger), a process of questioning, focusing and reflecting. No distinct difference was made between the analysing and data collection phases and he advocated that the two are done simultaneously.

Constructivist approaches such as Van Manen's have historically been subjected to claims by positivist researchers that they lacked rigour. Armour *et al.* (2009) concluded that rigour in qualitative research differs from positivist research by centring on demonstrating authenticity as opposed to reliability (the ability to replicate the research and achieve the same results). Armour *et al.* (2009) defined authenticity as research which clearly depicted that the conclusions reached by the researchers represent the experiences of the participants: the conclusions were logical and transparent. Armour *et al.* (2009) suggested that the honesty of including examples that were different from the majority of respondents was a way of demonstrating rigour (authenticity). Hermeneutic phenomenological approaches such as Van Manen's approach often advocated the use of the self, including one's own experiences, to help understand a phenomenon (Van Manen, 1990). Van Manen's approach was unconventional for its level of self-reflection, inclusion of personal anecdotes and, on occasion, the use of the first-person narrative within his writings. This was due to his central aim of using reflection to create a more direct contact with the experience as lived (Van Manen,

1990).

This use of self as a research instrument and the use of the first person narrative within research were regarded as a weakness by some phenomenologists such as Husserl. Sandelowski and Barroso (1986) emphasised that the language used in positive research is a neutral voice intending to show distance between the researcher and the phenomenon. However, in qualitative research, the opposite is true and the aim is to demonstrate the researchers' engagement with the phenomenon. The use of the first-person narrative in research has been criticised by some academics for fear that research would be seen as anecdotal and not 'evidence-based' (Webb, 1992). Creswell (1998) and Dahlberg *et al.* (2001) suggested such concerns could be addressed by producing an audit trail of analytical decisions and by providing a detailed description of the data.

I reviewed other researchers who had employed Van Manen's methodology to establish how they had written up their research. Robertson-Malt (1999) applied Van Manen's method to research patients' experiences of heart disease and wrote using a first-person narrative. This appeared congruent with her research design and the process which she described in detail, putting her own reflection and interpretation at the centre. Other researchers who used Van Manen's approach chose not to write in the first-person (Hilton and Henderson, 2003 and Thome *et al.*, 2005). To describe such a reflexive process with the researcher's interpretations at the centre in the third-person did not produce the same personal impact for me as Robertson-Malt's (1999) research. As a result, I chose to write my research using the first-person as this felt congruent with Van Manen's methodology and demonstrates how and why I had chosen to undertake various methodological decisions within the research planning process. My participants' stories and the exploratory thematic analysis and hermeneutic phenomenological analysis which highlighted my thought process and analytical decisions were included to demonstrate maximum transparency. Supervision was used to discuss my reflections and interpretations and for the opportunity for my supervisory team to challenge me in an open and direct fashion if my views appeared to be based on my preconceptions rather than what was presented in the narrative. A research diary was kept to explore my reflections and biases throughout the research process.

The method Van Manen used was spoken interviews, where people thought and described a 'concrete experience' which was explored in its entirety, ensuring the account remained personal and not general. Van Manen (1990) also focussed on what is not being said (like in psychotherapy) as this could be equally important in terms of

understanding a phenomenon. In the development of my own participant narratives I focused on what was not being said by participants in interviews and this was evident in the formation of my interpretations based on my own reflections and understandings. Van Manen incorporated anecdotes to assist in helping to 'make it real' for readers: these anecdotes were used to demonstrate how experiences of a phenomenon differed for individuals. As will be seen in the following chapters, my research utilised anecdotes and individual stories to describe the different types of relationships of people with learning disabilities and experiences based on their choices of partner. Van Manen's methodology valued giving individuals a voice, which was significant to my research that interviewed people with learning disabilities who had previously been denied a voice in research.

Van Manen (1990) advocated the use of interviews as the method for hermeneutic phenomenology. He saw the interviews used in his methodology as distinct from traditional research interviews, defining them as 'conversational interviewing'. Van Manen's (1990) conversational interviewing had two distinct purposes, which were 'a means of exploring and gathering experiential narrative material that may serve as a resource for developing richer and deeper understanding of a human phenomenon and the researcher may be used as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience' (p.66). Applying Van Manen's definition within the context of my research meant that interviews were employed as a means to gather the experiences of adults with learning disabilities about their relationships. However, it was the shared conversations between us that enabled me to gain a deep and rich understanding of how they experienced their relationships. Van Manen offered little guidance in terms of how these interviews should take place but advocated asking a person to think of a specific situation and then 'explore the whole experience to its fullest' (p.67). In terms of technique, Van Manen advocated asking fewer questions and using prompts to guide interviewees into deeper exploration. Due to the communication needs of the participants it was not possible in my research to have such open-ended questions and this is discussed further in the Section 3.6.

Van Manen's approach was developed to interview children, thus it may be considered by some inappropriate to use this approach with adults. As an educationalist he identified issues with working with this group, such as a limited vocabulary and poorer language skills, characteristics often displayed by those with learning disabilities (McCarthy, 1999). Van Manen used his interview data from children to write stories that reflected the phenomenon and brought the stories to life. The way in which he

analysed the data in-depth and presented it in story form with anecdotes enabled the reader to understand the phenomenon from the person's perspective. It would be patronising to compare adults with learning disabilities with children: however, since they can share language deficits, I considered the transferability of his methodology in depth. Van Manen offered an approach that maximised participants' narratives through the development of stories.

Van Manen (1990) advocated actively engaging with participants in their 'life world' and collecting such experiences as 'data', he defined this as 'close observation' (p.68). This was used to supplement interviews as a means of collecting different types of experiential material. He believed this was useful when gathering the experiences of individuals with limited communication. He argued that such observations contributed to a deeper understanding of an individual by observing their behaviours and interactions with others and their environment. The aim of close observation was to promote engagement and differed from traditional experimental or behavioural observation techniques which encouraged detachment from the situation by promoting engagement. Van Manen's approach aimed to 'enter the life world of the person whose experiences are relevant study material' (Van Manen, 1990, p.69) while maintaining a hermeneutic awareness of recognising the meaning in such situations. Data from a modified version of close observations were utilised to supplement the interview data and this is discussed in Section 3.6.5.

Van Manen (1990) advocated the use of personal biographies (life histories) as a resource for experiential material, claiming that 'by understanding more of each other's biographies we feel closer united' (p.71). He suggested that individuals read them to understand about people's lives, their origins, key influences and significant events. This concept was used as the guide in developing participant stories as part of my methodology which was congruent with Van Manen's approach. Information utilised to develop the stories was selected from interviews and the observations/interactions with participants and interactions with staff either on the day of the interview or via telephone/email when arranging interviews (see Section 3.6.5). These stories were then examined separately from the main narratives in the interviews (see Chapter 4).

### **3.6 Research Design and Implementation**

This Section explains the practical aspects of the research including who took part, the sampling method used, where participants were selected from and how the interviews were arranged and organised. It also discusses the choice of interviews as a method

and how this applied within Van Manen's methodology. The Chapter concludes with a description of the first interview undertaken and how this impacted on subsequent interviews.

### **3.6.1 Inclusion Criteria**

To be included in the research, participants had to fulfil a set number of criteria:

All participants had a learning disability (see Section 1.2) and were over 18 years of age.

All participants were recruited via a gatekeeper, a senior staff member within the 'Support Provider Organisations' working specifically with adults with learning disabilities. All gatekeepers were fully briefed regarding the inclusion criteria for the research.

I acknowledged the continuum of disabilities people could experience and considered how this mediates the types of relationships they encountered. People with profound and severe learning disabilities, including those who do not use speech to communicate, may have close relationships with others, however my research was focused on the relationships of people with less complex needs. The utilisation of close observation would allowed some aspects of non-verbal relationships to be identified but without interviewing them this would be a one sided assessment. I sought to ensure that my participants' voices were heard in their own words as much as possible. Therefore, participants had to be able to verbally communicate well enough to be able to discuss their relationship, thoughts and feelings with me in the interview. The gatekeeper initially ascertained this and was confirmed in pre-research interviews. No potential participant was excluded from the research because they failed to fulfil this criterion. One participant had a speech impediment which made the research challenging, but he was not excluded from the research. I was not aware of participants' diagnoses of mild, moderate, severe or profound learning disabilities (as explained in Section 1.2). However, based on their level of verbal ability, it could be inferred that no participant had profound or severe learning disabilities.

Participants must have had at least one 'long-term' relationship (6 months or more). This did not have to be sexual but had to be a long standing heterosexual romantic/intimate commitment. All participants met this criterion and all of participants' relationships exceeded this time frame.

### **3.6.2 Sampling**

Purposeful sampling was selected as the sampling method. The criteria of purposeful sampling outlined by Teddlie and Yu (2007) involves 'selecting units (individuals/institutions) based on the specific purposes associated with answering research studies questions' (p. 77). The 'units' in this research were people with a learning disability and the 'specific purposes' associated with answering research questions were that they had experiences of an intimate relationship. Purposeful sampling has been criticised by researchers due to its associated bias (Tuckett, 2004). Critics of this sampling method were concerned about participants' reasoning to elect to take part in the research, fearing self-selecting participants could have had a need to share 'extreme views' (either a totally negative or totally positive story) based on their experiences. This type of bias was not an issue for my research as I was employing a phenomenological approach exploring the experiences people have had and all were valued and relevant. Overall most participants in my research did not disclose such extreme stories and those that did were shared and not excluded from the research.

Random sampling, 'a sample in which every element in the population has an equal chance of being selected' (The Free Dictionary, no date) could have been used as a sampling method, however it was deemed impractical and unbeneficial to sample the whole learning disability population as, at present, people with a learning disability in a relationship are in the minority (Emerson *et al.*, 2005). It would have been likely that a number of people initially included in the research would have had no experience of a relationship and not met the research inclusion criteria. Gaining access to enough participants to allow the use of random sampling would have not been possible. It was very difficult to access the participants that took part using purposeful sampling despite contacting over fifty social care providers. To have accessed a wider sample would have been even more challenging. Purposeful sampling was defined by Teddlie and Yu (2007) as the best sampling method to use when interviewing difficult to access groups such as adults with learning disabilities in relationships.

#### **Recruitment Sources**

Working for a similar organisation as the provider organisations it was considered whether the research could take place within my place of work. However, this was rejected by me and my supervisory team on ethical grounds. It would have been more convenient to have accessed a sample there but being a known figure to all in my organisation was a concern in that staff could have felt pressured to encourage people to take part based on my involvement. Even though not every person is known to me it could have been seen as a conflict of interest and it was felt more ethically sound to

complete this research in an independent location.

### **Provider 1**

Provider 1 consisted of individuals living in a residential support setting in the south of England. Provider 1 was a large national charity which provided support to adults with learning disabilities in a variety of settings (registered care homes, supported living services and outreach support).

### **Provider 2**

Provider 2 consisted of individuals living in a residential support setting based in one London borough. Provider 2 was a small regional charity which provided support to adults with learning disabilities in a variety of settings (registered care homes, supported living services and outreach support).

### **3.6.3 Recruitment Method**

Contact regarding the research, prior to obtaining ethical approval, was at a Director/CEO level within the organisations. Contact was made prior to ethical approval to ensure that there were sufficient numbers who met my inclusion criteria within these organisations. They were sent copies of all the research information including the proposal outlining the inclusion criteria (see Appendix 2). Several discussions took place via telephone with the CEO in Provider 1 to ensure they fully understood the aims of the research, what it entailed and what I required from them as an organisation. A similar discussion took place, and in person, with Provider 2, with a Director.

### **Gatekeeper**

Gatekeepers were used in the recruitment of participants. These were senior staff that had regular contact with the participants. Gatekeepers had direct knowledge of the participants due to the level of contact and involvement they have with these individuals and, therefore, were able to recommend to me appropriate people to be involved based on their knowledge. The gatekeepers were the individuals predominantly responsible for meeting the needs of the participants as identified in Maslow's theory and presented in Figure 1 A. It was possible that there could have been some bias in relation to the gatekeepers: for example, there was a possibility that gatekeepers could have only offered the research to participants who they felt highlighted their organisation in a positive way. The research was anonymous so it had no impact on the company's public profile, but they may not have wanted to have shared participants' stories which did not highlight the organisation in a positive light with another social care



professional. This, however, seemed unlikely due to the participants sharing both positive and negative stories. The risk of gatekeeper bias was deemed acceptable as without them it would not have been possible to gain access to such a vulnerable group, to gain ethical approval and to ensure the appropriate individuals took part. In relation to Maslow's theory, gatekeepers were utilised to ensure peoples' 'safety and security needs' were met, ensuring that only psychologically robust people participated and that people were supported prior to interview to understand what was involved in taking part in the research.

There was an issue surrounding a gatekeeper in Provider 1 as one participant who relied on staff support to organise appointments did not take part in the second interview. Despite sending a letter and calling the agency it was not possible to get a second interview. It was unclear if this was a communication error between the gatekeeper and myself or if the person chose not to take part. There were also two participants who chose not to take part in the research despite showing an initial interest. As I never met with these individuals to discuss this it was unclear what led them to change their mind.

### **Ethical Approval**

I secured ethical approval via my university ethics board. More information on this is provided in the Section on informed consent (3.7).

### **Provider 1**

Once ethical approval was obtained, contact was made, via the CEO, with a senior manager within a southern regional office. She would serve as the gatekeeper for the research for Provider 1. The gatekeeper was sent copies of all the research information including the proposal outlining the inclusion criteria. The research criteria and ethical concerns were discussed via the telephone prior to the identification of participants.

The gatekeeper approached people in relationships via their staff, asking who initially enquired if they were interested in participating. Contact was initially made with interested parties via the Team Manager to arrange meetings and to discuss the research with each person. Ten potential participants were identified and eight met with me to discuss the research, either individually or as part of a couple. One person declined to take part in the interviews and did not engage in the pre-meeting. One person initially declined to take part as he was not going to be paid but changed his mind on the day of the interview.

The pre-meetings were an opportunity for people to meet me and establish if they would feel comfortable discussing topics which were personal, sensitive and emotional. It was also to establish if their verbal skills met the required level and their relationship experience was romantic/ intimate in nature and they were able to give informed consent to take part in the research (see Section 3.7.4 on informed consent). Participants were given the opportunity to ask questions and raise any concerns they had about the research. Participants were reassured that they were free to decline taking part and could do this at any point. I did not feel that participants had been pressured to take part as some of those initially identified went on to decline taking part. Some participants asked questions: one person wanted to know if I was going to film the interviews and I explained I was not and another person asked what would happen if she did not want to answer a question. I explained that this was fine and she was free at any time to say that she felt uncomfortable answering.

One couple was spoken to via telephone instead of a face to face meeting. They were given the same opportunities to discuss and ask questions as those who had face to face meetings. Their pre-meetings were conducted this way as these participants joined the research later, which posed time constraints. They lived in a different geographical location to all other participants and this was considerable distance for me to travel.

Following the pre-meeting, all of the participants were asked again, via the team manager, if they were happy to take part. No-one declined at this stage and meetings were arranged directly.

## **Provider 2**

Once ethical approval was obtained contact was made, via a Senior Manager, with a Team Manager who had identified potential participants. She would serve as the gatekeeper for the research for Provider 2. The gatekeeper was given copies of all the research information including the proposal outlining the inclusion criteria. The research criteria and ethical concerns were discussed in person prior to the identification of participants.

The gatekeeper approached people who they were supporting and who were in relationships and enquired if they were interested in participating. I had met with the Team Manager and some participants prior to this during some contact work I was employed to undertake within their organisation. I had no direct contact with potential participants. Five potential participants were identified. One person was deemed

unsuitable for the research as his only relationship experience was in an abusive relationship. Despite his interest both the gatekeeper and I felt it would have been too traumatic for him to take part. Another person was excluded from the research as she recently 'assaulted' an ex-partner's girlfriend. The gatekeeper was concerned that discussing this relationship may increase her aggressive behaviour. The gatekeeper fulfilled their obligation of protecting the 'safety and security needs' of both the person who may have found the interview too traumatic as well as other individuals who could have been at risk from aggressive behaviour had they participated. Three people agreed to take part. As with Provider 1, all of these participants had a pre-meeting to discuss the research. Following the pre-meeting participants were asked again, via the Team Manager, if they were happy to take part. No-one declined at this stage and meetings were arranged directly.

### **3.6.4 Method - Interviews and Interview Guide**

The aim of this research was to explore what people with learning disabilities look for in a potential partner and understand how their prior experiences affect their choices and influence the relationships they experience. To achieve this it was necessary to engage with participants directly face-to-face via interview. It would not have been possible to conduct this research any other way as I was required to collect a narrative account of participants' experiences and interviews gave me access to this. Van Manen (1990) advocated that participants' narratives could be collected via asking them to produce it in a written text. This was considered as a possible method. However, often people with learning disabilities have difficulties in this area, making it unlikely that the amount of data required would be collected in this format. People with learning disabilities often have a limited vocabulary and poor language skills, making the use of a language-based approach challenging, but interviewing was the most effective way to obtain the level of detail required from participants. Other researchers such as McCarthy (1999) and Lesseliers (1999) have used language-based approaches and interviews to research similarly sensitive topics with people with learning disabilities.

Group interviews and focus groups were considered. However, due to the sensitive nature of the research, it felt inappropriate to conduct them in that format as individuals may not have felt their 'safety and security needs' were upheld by the researcher due to the lack of privacy. The topic area was also deeply complex, exploring one of the most intangible aspects of human existence. It would have been difficult to penetrate to such a depth in a group setting. Participants also shared painful memories of abuse and may not have been so open if other people were present. Participants also had the

same support provider and most were known to each other, which could have been an issue regarding confidentiality.

In-depth interviews were selected as the research method with participants being interviewed either alone or as part of a couple. People with learning disabilities were provided with an opportunity to share their personal experiences of intimate relationships. Interviews were seen as the most appropriate method as they enabled access to the intimate world of the participants. Hill *et al.* (2001) supported this, believing that it is the human aspect of interviewing which makes it a superior method when exploring the experiences of others, suggesting this is due to the engaging nature of the interview which comes from a discussion with an attentive and interested listener. Meeting with participants at least twice enabled me to develop a rapport and a relationship with each person. If the interviews had taken place in a group setting or by telephone I do not think the same level of intimacy would have been achieved and the depth contained within the interview would have been reduced. Also, due to the varying levels of verbal and comprehension abilities among the participants, a group setting would have been difficult to manage to ensure each person had an equal say. It would have been likely that more able participants would have dominated the group interviews or focus groups. The intimate interview setting enabled me the opportunity to modify my vocabulary based on the needs of the participants. I was able to ask some participants the same questions that I would ask people without learning disabilities, while others required much simpler language.

Van Manen (1990) warned researchers about letting 'method ruling the question' (p.66). This was described as when the interview resulted in shorter responses and a lack of narrative, stories and anecdotes. Van Manen (1990) suggested that this would lead to the researcher over-interpreting or including more of their own personal opinions in the narrative. There were some initial concerns regarding the level of rich data which I would have been able to collect based on the communication difficulties inherent within my sample group. McCarthy (1999) identified the communication skills of people with learning disabilities as an issue within research due to their limited conversational skills and tendency to reply with one word answers, making narrative analysis difficult. Half the participants in my research had limited difficulty expressing themselves and were able to talk about a range of topics, including more abstract concepts such as feelings, and required less prompting. However, the other half frequently replied with short answers and required more input than just prompts. All of the participants lacked the ability to speak at length without direction. One pre-meeting identified a participant in Provider 2 with the lowest verbal ability who had difficulty

focussing and expressing herself. CHANGE picture bank cards were used to facilitate the interviews (see Appendix 3), which were accessible images produced in collaboration with people with learning disabilities to aid discussion. These were used to focus her attention and act as a visual aid to the topics we were discussing. I felt that despite the participants' communication difficulties the level of stories, narrative and accounts of personal experiences were sufficient and rich enough to meet the criteria for Van Manen's (1990) 'conversational interviews' (p.66).

### **Interview guide**

The methodology of Max Van Manen did not advocate the use of a fixed interview schedule. The research proposal instead outlined the use of an interview guide with general topics and prompts, however, in practice, this proved challenging. Van Manen stated that the 'conversational interviews' for his methodology used little direction from the interviewer and that the interview was an open space for the interviewee to share their experiences. This lack of direction/ exploratory nature posed a challenge when interviewing people with learning disabilities. Some researchers such as Gates and Waight (2007) insisted that more direction (compared to interviewing the people without learning disabilities) was necessary to facilitate a meaningful interview. Others such as Walmsley (2004) and Chapman and McNulty (2004) opposed this view. Gates and Waight (2007) were concerned that without direction participants would not be able to remain on topic and produce material relevant to the research question. There was an initial concern that this may also be an issue in my research but it was unfounded.

Based on the experience of conducting the pre-interviews meetings an interview guide was developed for the first interview which included a list of potential topics and prompts (see Appendix 4). In line with Max Van Manen's (1990) methodology participants shared an aspect of the phenomenon which was then explored to its fullest in the interview. Van Manen advocated asking fewer questions and using prompts to guide interviewees into deeper exploration. I did ask questions when there was a lack of direction in the conversation or a prolonged silence. However, I felt that I often had to ask more questions than advocated by Van Manen due to the communication needs of the participants. The interview prompts were helpful as a researcher in that it gave me a list of topics to ask participants if they could not be prompted to expand on a topic. Most topics included on the list were asked in the interview: however, the interview format was not rigid. Participants guided the interview as much as possible and if a topic did not relate to what was being asked in the interviews it was not asked.

Following the initial interview there was a period of reflection and a new guide was

developed based on follow-up questions (specific to the individual) to material raised in the first interview and any missed topics covered in other interviews. This process happened for both the second and/or third interview. This gave the research a cyclical, reflective nature that had not been intended when designing the research, although it was allowable within the terms of the ethical approval. This was congruent with Van Manen's reflective version of hermeneutic phenomenology and provided a way of achieving the systematic questioning that he advocated in *Researching Lived Experience* (1990). Due to their disability participants did not have the same reflective skills and lacked the ability to talk for the same length about abstract topics such as love and relationship as their peers without learning disabilities. The re-visiting of topics allowed participants to more fully cover topics and experiences too large for them to include in one interview and a few participants commented that they had had time to think about their experiences and reflect between interviews.

### **3.6.5 Research Interviews and Observation**

#### **Location of Interviews**

Historically, attendance has cited as a practical issue within learning disability research. Many participants are dependent on others for transportation which results in participants not being able to attend sessions due to lack of transportation (Gates and Waight, 2007). There were further confounding issues surrounding participants' ability to arrive at the research location on time due to their disability, such as poor timekeeping skills (Gates and Waight, 2007). To limit these issues the interviews took place at the location of their choice. Interviews took place in a private room in the participant's home other than one first interview with Provider 1 which took place in a local office. For health and safety reasons I was not alone with participants for any of the pre-meetings. All participants except two (Kerry and Dean) lived in group environments where there were always staff present in the buildings. A staff member met with Kerry, Dean and I for our initial meeting but I then met them both together in Kerry's flat. I was unable to meet Dean alone and I was advised by the Manager that their risk management plan advised against me seeing him alone. It was unclear why this was. I was informed that it was fine to visit Dean while he was with Kerry and he was no risk to Kerry.

#### **Provider 1**

Each interview lasted approximately one to one and a half hours, with all participants in

this group interviewed on two occasions with the exception of one participant whose contact was lost after the first interview and another who did not attend as planned. No staff members were present for the interviews. This support was offered but the participants declined. It was initially offered to help participants feel more comfortable in interviews or to assist in helping participants to understand a question. No participant in this group felt the need to have staff present in the interview, believing they could cope without staff assistance. One couple stated that they would not have liked staff present as it would have been embarrassing to discuss such personal issues in front of them.

Staff presence in the interviews could have had a positive effect for the reasons outlined above. However, I felt that staff presence could have had a more detrimental effect. It could have affected the topics participants felt comfortable discussing or were willing to discuss, such as the influence of paid staff on their relationships or others with whom staff have relationships such as families or housemates. Four couples were interviewed in this group and interviewing two individuals had benefits while also posing some challenges. It was beneficial as it allowed me to observe how the couples interacted within the interviews, including communication, affection and how they dealt with discussing sensitive issues or conflict. This contributed to my understanding their relationships in conjunction with their narratives obtained in the interviews. Some participants could have dominated the interview as they were able to talk at length and their partners required prompting to be included fully within the interview. Therefore, there was a need for skilled facilitation within the interview process to ensure both parties contributed equally.

## **Provider 2**

Interviews in this group were shorter due to the needs of the participants and interviews lasted between 45 minutes to one hour. Based on my observations from pre-interviews, participants in this group had lower verbal and comprehension abilities and appeared to have shorter concentration spans. Both participants in this group were interviewed on three occasions.

A key worker was present during one of the interviews with a female participant (the male participant declined this support). This was during the second interview as I had found the initial interview challenging in terms of ensuring that the participant understood my questions so I wanted the staff present to ensure my participant understood the questions: she could be available to re-phrase any questions. The female participant was asked if she was happy for her key worker to be present, to which she agreed. I did not invite the staff member to subsequent interviews as I felt

her presence was not conducive to the interview process due to the way she interrupted and posed unnecessary questions to the participant. One participant had a severe stammer which required a modified interview style with a more patient approach that allowed the individual sufficient time to respond alongside writing detailed notes in case the audio recording was unclear.

### **Reflective diary**

A diary was kept throughout the research interview process. This was to record close observations and other reflections. I allowed myself time before following interviews to capture these and note similarities with other participants' stories; common elements; the main themes of the interview; what the most important thing was that I heard or felt in the interview and how what I heard about participants in the interview related to what I already knew about them. All these items were written about as soon as possible so they were fresh in my mind and not confused between different participants. I also recorded any physical sensations I felt at the time and any observations that I saw in the interviews, such as physically feeling anxious or tearful when hearing stories of abuse and rejection experienced by some participants. Van Manen's (1990) methodology placed significant emphasis on the importance of the researcher within the research and how their own understandings and experience guides their interpretations, and therefore it was important to record my own thoughts and feelings in the reflective diary as they would be important when conducting my analysis. This is explained in more detail in Section 3.8.

### **Close Observation**

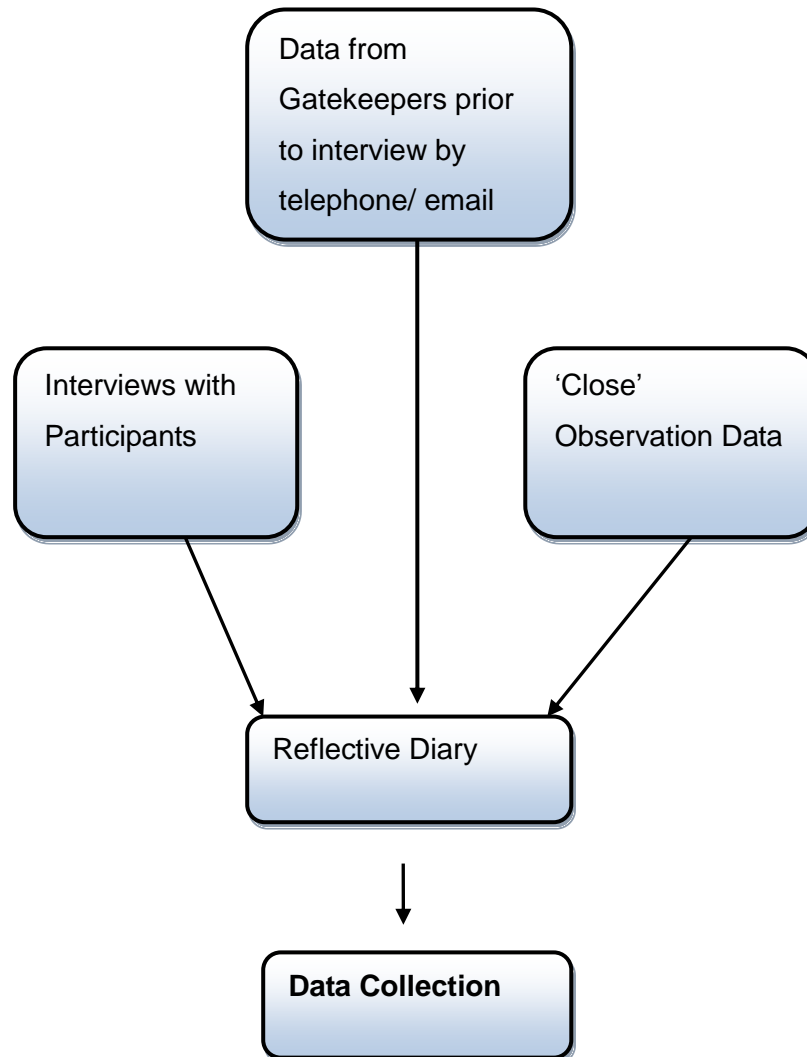
A modified version of 'close observation' (Van Manen, 1990) was utilised to supplement interviews by collecting additional experiential data relevant to the phenomenon and to add depth to participants' stories. Van Manen (1990) advocated this could be achieved via engagement with the participants' 'life world'. Van Manen's 'close observation' was modified for my research in regards to the level of engagement with participants' 'life world'. My engagement levels were lower than those employed by Van Manen. I spent an average of ten minutes in participants' homes pre/ post interviews. During this time I was typically sat waiting for participants to begin the interview, sometimes speaking with them and their staff (not regarding the interview topic) or observing what was happening around me. I used this time to gain a more holistic view of participants, understanding where and how they lived, how participants interacted with others (including their housemates and staff) and their environment. This contributed to a deeper understanding of an individual or couple. Additional information staff disclosed in arranging the interviews, either by telephone or email, was included as data. All



information was noted in my reflective diary as soon as possible after the interaction or interview had taken place.

Staff members or housemates were not asked to provide individual consent to being observed as my contact with them was minimal and no individual, other than the participants, was discussed in the findings. The focus of the observations was to witness how participants interacted with others such as their partner, housemates, staff and their environment. Consent to this was implied and covered within the agreement provided by the provider organizations to allow access and for them to act as gatekeepers. With the exception of one staff member being present in one interview (merely to assist me if I felt the participant did not understand my question), staff were not included in interviews. Staff were not asked to provide any 'pre-interview' information. Staff input related purely to observational elements, which included my observations when I met them during my visits to the properties or what they disclosed to me during our interactions together either when I was arranging interviews or visiting the house to interview participants. What they shared and how they interacted with participants assisted me in understanding the relationship they had and attitudes they held regarding the participants. Staff were not interviewed as their views were not relevant to the study aims. Figure 2 depicts how the different data collection sources interacted and contributed to the overall process of data collection.

**Figure 2: Data Collection**



### **3.6.6 The First Interview**

Consideration was given to the employment of a pilot study, however Van Manen (1990) made no reference to the use of a pilot in his writings which was understandable due to the exploratory nature of his methodology. The use of a pilot is more common in research employing instruments to be trialled such as in questionnaires and there was no such instrument in this research. It was evident that a pilot study was not congruent with the research design.

There were a number of problems encountered in my first interview and my supervisory team and I decided that this would be used as a form of pilot where a period of reflection and evaluation could take place prior to any subsequent interviews. This process was intended to address the concerns raised in the first interview and assist in the preparation for subsequent interviews. The whole 'first interview experience' was

written up as a report and discussed in supervision (see Appendix 5), including how I utilised this experience to improve the quality of subsequent interviews.

### **3.7 Ethical Issues**

This Section outlines the main ethical issues identified within my research. This includes the intrusion of the research on participants' lives, how the research could have affected participants' wellbeing, confidentiality and informed consent, including how this was particularly important when working with people with a learning disability.

#### **3.7.1 Intrusion of the Research**

The research involved interviewing vulnerable people over a period of time about the intimate details of their personal relationships. Most participants were interviewed two or three times and interviews lasted approximately 45-90 minutes. This commitment was explained from the outset in the pre-meeting, along with explaining the role of the interviewer and the interviewee and what was expected of both parties. There was a concern that some participants could have found sharing this level of personal detail difficult or upsetting and the interview process intrusive. In an attempt to alleviate the intrusion, participants were all interviewed at a time and place that was convenient for them (and safe for the lone female researcher to attend). To ensure their 'safety and security needs' were not compromised participants were given control to end the interview at any point. Throughout the course of the interviews no participant asked for their data to be removed. No participants showed any outward signs of distress such as crying. Two participants did not take part in a second interview. Alan's staff did not respond to my telephone messages or emails and Dean did not attend when interviews were arranged. I tried to contact them to ascertain their reasons for not taking part but, despite my efforts, I never received any feedback.

There was a concern participants may have become distressed when the research ended, possibly due to a temporary reduction in feelings of loneliness that the interview process may have caused. Many people with a learning disability have limited social networks and a high degree of loneliness and a lack of close relationships (Nunkoosing and John, 1997). Northway (2000) addressed this issue and stated that researchers needed to ensure that both parties were clear regarding their expectations about the level of involvement that they would like. The interview process was made clear to participants and I explained that I was only there to conduct the interviews and would be unable to maintain regular contact after the research had ended. Participants were

told they could email or phone if they wanted but no participant took up this offer. I was aware there was an imbalance of power within the relationship, with me being privileged to a vast amount of information about the participants who knew relatively little about me. This would not have been a sound basis for maintaining an equal friendship.

I hoped that that any feelings of intrusion or rejection participants felt would have been outweighed by the positive aspects of taking part in the research. I hoped that they found taking part in this research a rewarding process, having had space to share their feelings and be listened to over a period of time. Potentially, involvement in the research increased participants' 'self-esteem needs', by building confidence, a sense of achievement and recognition (as outlined in Figure 1A). I hoped that the interviews had created a space for personal development and that participants had gained a better understanding of themselves and their relationships through the self-reflection that they engaged in during interviews.

### **3.7.2 On-going Support**

Participants were made aware prior to the interviews that there was a possibility that they could have become upset during the interviews and were asked to think about what they would do if this happened and think who they would be able to talk to about it. In addition, information was made available to the participants regarding local agencies they could contact (such as Respond) if they required more professional help to discuss issues arising from the interviews. During the course of the interviews, I drew upon my twelve years' experience working with people with learning disabilities. No person appeared to be affected by the emotional content discussed. No person cried or appeared distressed. When two female participants discussed abuse they had experienced in the past, it was their partners who provided them with emotional support in the interview by offering both verbal reassurance and holding their hands when this was happening. One person appeared to get defensive in the interview and was asked if she wanted to stop but she claimed she did not wish to. The interview continued but was stopped when she continued to appear un-cooperative. This was done in a non-confrontational manner by informing her that I had all the information I required, thanking her and stating I had to go to catch my train.

### **3.7.3 Confidentiality**

Each participant signed a consent form at the beginning of their first interview (see

Appendix 6). If they were unable to sign they made their own unique mark. The consent forms were highly confidential as it was possible to identify the participants from these. They were stored within a locked cupboard in my office, where only I hold the key. The audio data was transcribed using a digital voice recorder and these audio recordings and the transcripts were held electronically on my work laptop. The computer was encrypted and password-protected, the only other parties having access to this were my organisation's IT department, who have signed a confidentiality agreement as part of their terms of employment.

There were no names recorded on any of the transcripts: therefore a pseudonym was used for each participant. Once the interviews were arranged and conducted any emails regarding the names or addresses of participants were shredded and deleted. Their records will be kept for 7 years from the date they were recorded (the legal requirement) and then destroyed. The audio files will be deleted and written documents will be shredded by a confidential waste company. The transcripts were not shared with any other parties except the supervisory team (although they did not know the identities of the participants). Original transcripts could be requested by the university/ examiners and publishers for verification purposes: if so transcripts would be anonymised and any distinguishing information (such as what people look like, identifiable characteristics/ features or where they lived) removed. Participants were offered copies of either the transcript or the digital recordings (if they were unable to read) but all declined this. The data belonged to the participants who had the right to withdraw their information at any point before the research was submitted. They were told if they chose to do so the data would be destroyed and not used in the research.

### **Breaches to Confidentiality**

Consideration was given pertaining to what action would be taken following an allegation of abuse of a vulnerable adult. It was decided if such an allegation occurred involving any of the participants, it would not have been possible to keep this confidential as the participants were defined as vulnerable adults (DoH, 2000) so there was a duty of care to disclose any allegation. During interviews I was obligated to ensure their 'safety and security needs' were not compromised by informing those responsible for safeguarding if necessary. This was discussed with the participants in the pre-meetings and again just before the first interview began. They were informed that if such disclosures had occurred, we would have discussed it together in the interview before any disclosures were made. Disclosures would have been made to their Team Manager or another staff member if they were not available. I would have either allowed them to disclose it (with my presence to ensure it was done) or to have

disclosed it myself if they preferred this or were unwilling to. An accessible document about confidentiality and consent was read and explained to participants during the initial meeting (see Appendix 7).

There were no disclosures of unreported or current abuse throughout the course of the interviews.

### **3.7.4 Informed Consent**

Once potential participants were identified via the gatekeeper, each person/couple was met individually to go through the research and explain what the research entailed, and this allowed participants to ask any questions they had. In the pre-meetings I was mindful regarding my communication with each person, I used simple, clear and jargon-free language. I had twelve years' experience of communicating in this way due to my various job roles where I communicated with individuals with varying degrees of disabilities and communication needs. My previous experience enabled me to develop good observational skills around non-verbal communication. I was observant in these pre-meetings as to whether participants displayed negative indicators (such as lack of eye contact, disinterest, withdrawing or being aggressive/ irritated) as this would have been a good indication that the person did not wish to take part in the interview. This did not occur during the pre-meetings and all participants appeared engaged and eager to take part in the research.

Informed consent was an important ethical issue within my research due to the needs of my participants. There was an initial confusion over which level of ethical approval was required. Due to the vulnerability of my sample group it was initially suggested to me by my supervisory team to apply for ethical approval at my local Research Ethics Committee (REC). There was a concern that my participants could be deemed as 'unable to consent' due to their learning disability. Under the Mental Capacity Act 2005 participants need to have the capacity to consent to take part in the research and understand the implications of doing so. I did not feel that the people I intended to interview would match this definition as the inclusion criteria outlined that they would have to be able to communicate sufficiently to be able to discuss sensitive issues including more abstract concepts such as feelings and already be involved in a relationship suggesting a lower level of impairment. I applied to my local REC which informed me that I did not need to apply to them as they felt from my research outline that it did not appear that I would be including anybody who lacked the capacity to consent and would therefore not invoke the MCA (see Appendix 8 for email copy). They

suggested that review by my university REC should be sufficient. Ethical approval was secured with only a minor amendment required on my participant information sheet (see Appendix 9 for final version).

As a researcher it was paramount that I ensured my participants were able to make an informed decision to take part in the research and that they did not lack capacity. I used the pre-meetings to ascertain participants' understandings of the implications of the research and to determine if they were making an informed decision. In the pre-meetings participants were briefed in detail about how the research could have potentially made them feel and they were given space to discuss any concerns they may have had about this. No participant appeared concerned about this. People were asked 'why shouldn't they take part'? This question was asked to help the researcher to judge how much participants understood about the potential risk to them in the research. Participants were also asked 'why do you want to take part in the research'? They had to provide an answer which reflected their own wishes rather than that of someone else such as a staff member or parent. All of the participants were able to do this. Most of the participants expressed a desire to share their story if it helped others. Based on the participants' responses in the pre-meetings I felt that they all were able to understand what the research was about, the risks of participating, confidentiality, anonymity and, simplistically, what I intended to do with their narrative.

Participants were free to withdraw at any time. I removed one participant from the research, in consultation with her staff team, as, during the first interview, she was unresponsive and did not really engage with me. She had been happy to engage in the pre-meetings but had subsequently experienced a period of poor health (physical and mental). The few comments she made in the first interview were removed from the transcript but she was still given a voucher for taking part.

All the relevant research literature for the participants, such as an explanation of the study, forms and confidentiality agreement, was in an 'easy read' format. As part of my paid employment, I had access to 'picture banks' produced by CHANGE, as well as access to a team of Involvement Managers who specialise in making complex information understandable to people with learning disabilities. Research by Ham *et al.* (2004) involved people with disabilities as co-researchers: their input gave a valuable insight into what people with a learning disability viewed as important when producing 'research literature'. They said that it was important to supply enough information so that people knew what the research was about 'but not to provide too much information that people might find confusing' (p.402). They also thought it was important to add

photos of the research team to identify them to potential participants.

Considering Ham *et al.*'s (2004) research I kept the information brief and included a recent picture of myself (see Appendix 9). I had access to a group of people with learning disabilities with experience of reviewing policies and easy read documents who provided feedback on the accessible material I produced. These individuals read the accessible material and gave feedback on its accessibility and whether they found the participant information documents easy to understand, but they were not involved in any other aspect of the research. The feedback was that the information was easy to understand and no amendments were required.

### **3.7.5 Reward**

A £10 high street voucher was paid at the end of the interviews and participants were not told until this point that there would be a reward for their participation. This ensured the reward did not act as an incentive to participate but rather as a 'thank you' for their time and valuable contribution. It was given or mailed, along with a 'thank you' card to all participants regardless of the number of interviews they participated in. Historically, people with learning disabilities have not been paid for their contribution to research and it would feel unethical not to recognise that their time and contribution is worthwhile and valued. Taking part provided an opportunity to engage in, what could be considered, a socially valued role as a valued and respected participant in academic research. It would have been unlikely that my participants would have understood the respect given to academic research, but receiving money may have suggested to them they had done something which is socially valued.

## **3.8 My own process of hermeneutic phenomenological reflection**

In '*Researching Lived Experience*' (1990), Van Manen suggested a process for researchers who wished to follow his method and this was this process which guided how the participants' narratives from interviews were analysed.

Van Manen (1990) associated 'data' or its 'collection' with 'quantitative overtones associated with positivistic social science approaches' (p.53). He did, however, acknowledge that this was something all researchers 'did' regardless of the terminology used, so defined that the 'data' of human science research were 'human experiences' (p.63). Van Manen's (1990) methodology was based on the production of an 'original



text' (p.63). This text formed the basis for the hermeneutic phenomenological reflection where the aim was to understand the true essence of a phenomenon.

Like other narrative approaches such as Interpretive Phenomenological Analysis, Van Manen's methodology advocated the reviewing of narrative accounts in written form to identify themes. However, it was how this was applied in practice that identified his approach as being different. Van Manen (1990) considered traditional thematic analysis as too clinical: he defined it as 'the mechanical application of some frequency count or coding of selected terms in transcripts' (p.79). He advocated a less restricted, freer process and saw themes as the 'experiential structures that make up that experience' (p.79). Van Manen defined research as the process of writing about participants' themes to produce a textual description, questioning this description to produce new understanding, using your own knowledge and the experiences of others to interpret what was said to produce a deeper understanding of a phenomenon.

Van Manen's methodology, like most other narrative approaches, advocated a period where the researcher immersed themselves within the data. In my research this immersion in the data took place over many months. Outsourcing the transcription of the interviews had been considered due to its time-consuming nature. However, I rejected this notion early in the research design stage. This would have significantly decreased my involvement and I would have missed an opportunity to engage with the participants' narrative and, through typing the words, really knowing what the participants and I had said during the interviews. Transcription, while a time-consuming process, was vital in allowing me to become familiar with the narratives. Throughout the transcription process I made numerous notes within my research diary which were fundamental in identifying themes. Following the writing of the transcripts I spent approximately three months reading the transcripts and repeatedly listening to the audio files. I downloaded them to a secure MP3 player and listened to them while travelling. Again, throughout this process I continued to record any thoughts or feelings emerging from the data within my reflective diary. Although this occupied considerable periods of time it proved a valuable method for reflection and distilling my findings.

Using Van Manen's creative approach to theme identification I began reading the transcripts to identify themes which captured the experiences of participants. Van Manen identified three approaches to reading the transcripts and this was the process I followed. In *Researching Lived Experience* (1990) Van Manen advocated that researchers looked at:

- The text as a whole - trying to capture the most significant aspect of the text/its fundamental meaning.
- The selective or highlighted approach - The statements which appeared particularly significant.
- The detailed approach - where every line was looked at to see whether it was significant to the phenomenon being explored.

As part of the hermeneutic phenomenological reflection I read and reflected on the content of the texts in all three ways. This was undertaken in a forensic manner. As part of this process I examined the content of my reflective diary (see Section 3.6.5). This was very useful when considering what my 'experience' was of the participants, how it felt to sit with them, how they interacted with me and each other, including their body language and the atmosphere in their home. This was information about the phenomenon that I would have been unable to get from their transcripts yet I was able to incorporate it into the research. I was able to feel real warmth from some couples, identify hostility from one participant (which, after hearing her story, I attributed to defensiveness due to the abuse she experienced) and also experienced tension between housemates within the home. The diary also included information from my 'close observations' (see Section 3.6.5).

Van Manen (1990) identified how 'certain experiential themes re-occurred as commonality in the various descriptions' (p.93). Over time themes began to re-occur within my descriptions. Van Manen (1990) stated that a researcher had to select appropriate phrases or by capturing single statements which represented that theme. Van Manen advocated capturing thematic statements into 'phenomenologically sensitive paragraphs' (p.95). I created a spread sheet to organise themes and statements/words that related to them. This was not advocated by Van Manen and it could be considered mechanical by his methodology, however, this helped me organise my thoughts, research and writing.

It was difficult to know when to stop the process of looking for themes. I was keen to move on from this stage and begin writing, however, I wanted to be sure that I had really given my participants' experiences the time and attention they deserved. Van Manen gave no indication of how long researchers should spend in this period so I had to rely on my own judgement and guidance from supervisors. The transformation of themes into a text was a long process. It made me realise that the process of identifying themes was not done separately from the writing process: writing is part of the hermeneutic phenomenological reflection and themes are continually identified and

reflected upon in the writing stage. Early on, it was clear that there was more than one text to be written and the three different ways the data were analysed is presented in Table 5 below, identifying how they integrate with Van Manen's methodology.

**Table 5: Types of Analysis Utilised**

Chapter	Purpose	Integration with Van Manen
Chapter 4 Development of Participants' Stories and Exploratory Thematic Analysis	Written stories (not including direct participant quotes) which provided a real and personal context for each participant. Enabling the reader to understand their experiences of what it was like to be a person with a learning disability in a relationship.  Historically people with learning disabilities have been excluded from research and I wanted this ensure that their stories were heard and central to the research	Van Manen advocated the use of personal biographies claiming they could make a reader could feel closer to participants. He believed they enabled readers to have a better understanding of people's origins, key influences and significant events.
Chapter 5 Hermeneutic Phenomenological Reflection	To identify themes in participants' narratives and direct quotes from participants utilised to illustrate themes.	The main method outlined in Van Manen's <i>Researching Lived Experience</i> . Van Manen advocated the use of anecdotes and quotes from participants to bring themes to life and demonstrate diversity among participants.
Chapter 6 Key Developments in Policy, Practice and Attitudes	Exploring how the historical, social and political attitudes influenced the lives of participants. Considering how this impacted on the development of their intimate relationships.	Van Manen claimed context was central in understanding phenomena including the social and historical context. Chapter 6 provides this context.

In conclusion, Chapter 3 has highlighted how participants were identified and recruited and outlined ethical issues including the inherent difficulties of involving people with a learning disability within research. I discussed how Van Manen's methodology was selected and applied and how I interpreted his process of hermeneutic phenomenological reflection to identify the essential themes within my participants' narrative. Reflexivity was demonstrated throughout by justifying how decisions were made.

Chapter 4 focuses on the findings of the study and is in two parts. The first Section sets the scene for the research, introducing the participants and explaining where they

came from and who took part. It discusses their own unique stories including their history and family background and how they experience being a person with a learning disability in a relationship. The second Section of Chapter 4 presents an exploratory thematic analysis of participant stories including themes such as attachment, abuse, abandonment and protection and autonomy in relation to abuse. Themes within the exploratory analysis will be examined in relation to the two key theories: attachment theory and Maslow's theory.

## **Chapter 4 - Setting the Scene**

The aim of this Chapter is to 'set the scene' for the research and introduce the eleven participants who took part in the study. The Chapter includes two parts: the introduction of the participants and secondly, an exploratory thematic analysis which considers the facilitators and barriers to forming relationships.

The first Section of the Chapter (4.1) outlines information for the two provider organisations including geographical location, socio-economic factors and cultural diversity. It introduces the participants, including their key demographic information. Appendix 10 presents the participants' biographies which were developed (utilising the combination of data sources outlined in Figure 2) to tell the story of the participants and their relationships. This was to enable readers to understand the experiences of what it was like to be a person with a learning disability in a relationship.

The second Section of the Chapter (4.2) discusses the facilitators and barriers to forming relationships identified by the exploratory thematic analysis. These included abuse, attachment, abandonment, protection and autonomy in relation to abuse. Section 4.3 examines the themes in relation to Maslow's theory (1943), including the challenges the participants faced in their everyday existence in addition to having learning disabilities, and how these challenges impacted on their ability to meet the levels identified in Maslow's hierarchy (Figure 1A and 1B).

### **4.1 Introduction of the Participants and Participants Stories**

#### **Provider Organisations**

There were two support provider organisations who took part in the research: they were called Provider 1 and Provider 2.

#### **Provider 1**

Provider 1 was a large national charity support provider. The participants in this group came from two areas: the first was from the south coast (two coastal towns and the surrounding area) and the other was a large town in the south of England.

There were seven participants who came from the south coast living in small seaside towns or outlying smaller towns/villages. These locations appeared to have a higher than average percentage of people who were over 65 years old with a high percentage

of retirement bungalows and nursing homes. Visits to these locations suggested that there was little ethnic diversity and that most inhabitants were of White British origin. None of the properties visited were in poor, run-down areas. With the exception of Kerry and Dean who lived in flats, all of the participants from the first location lived in large suburban houses with drives, clean and wide roads free from vandalism and all properties were either semi-detached or detached. All of the properties appeared spacious, nicely furnished and well-maintained. Kerry's flat was visited, which was in a similar neighbourhood and was furnished and decorated well. Dean's flat was not seen. Four participants were within walking distance of the town and three participants were able to access the local town quickly via public transport; no participant drove.

The other two participants from Provider 1 came from a large town in the south of England. This area was not investigated as fully as the towns on the south coast, as the property was some distance from the station and a taxi was taken which by-passed most of the surrounding area. The property was on the outskirts of the town in a council estate. The property, while maintained well, was in a less affluent part of the town. The house was smaller than those seen on the south coast and a little cramped for four people and staff. Visits to the area suggested that there was less ethnic diversity compared to more urban areas and the majority of inhabitants were of white origin. All staff encountered in the interviews were of white origin. These participants accessed the town via public transport as no participant drove.

### **Provider 2**

Provider 2 was a small, locally-based charity in London. All three participants from this provider lived in a Victorian House which had been converted into flats. The house was in a conservation area, in contrast to some of the surrounding area which was less affluent. This location had a combination of affluent middle class areas as well as poverty and deprivation, like most London boroughs. The property was well-furnished and maintained but considerably smaller than the properties in first Provider group, as one person lived in a bedsit rather than a flat. The borough was ethnically diverse with a large African population and this was reflected in the staff encountered over the course of the interviews. These participants had easy access to all the amenities that city living allowed and numerous transport links. None of the participants drove.

### **Participants' Stories**

Van Manen (1990) utilised his interview data from children to write stories which reflected the phenomenon and brought their experiences to life. The way in which he analysed the data in-depth and presented it in story form with anecdotes enabled

readers to understand the phenomenon from the person's perspective. The data from the eleven research interviews was used in this way in an attempt to replicate what Van Manen achieved in his research. Table 6 provides key information about the participants and the participants' stories are located in Appendix 10.

**Table 6: Key Information about Participants**

Pseudonym	Age	Provider	Status	Living Arrangement	Meeting	Interview 1	Interview 2	Interview 3
Alan	60 +	Provider 1	Married	With Wife in shared Supported Living house	18/04/11	09/05/11	No contact	No contact
Kerry	Under 35	Provider 1	Engaged	Alone with some support	18/04/11	09/05/11	31/08/11	Not required
Dean	Under 35	Provider 1	Engaged	Alone with some support	18/04/11	09/05/11	No contact	
Caroline	35-60	Provider 1	Partner	With Partner in Registered Care Home	18/04/11	09/05/11	31/08/11	Not required
John	35-60	Provider 1	Partner	With Partner in Registered Care Home	18/04/11	09/05/11	31/08/11	Not required
Emma	Under 35	Provider 1	Engaged	With Fiancé in Registered Care Home	18/04/11	24/05/11	31/08/11	Not required
Liam	Under 35	Provider 1	Engaged	With Fiancée in Registered Care Home	18/04/11	24/05/11	31/08/11	Not required
Mary	35-60	Provider 2	Partner	Alone in Supported Living Flat	07/09/11	29/09/11	12/10/11	28/10/11
Peter	35-60	Provider 2	Married	With Wife in Supported Living Flat	07/09/11	29/09/11	12/10/11	28/10/11
Participant Withdrawn	35-60	Provider 2	Married	With Husband in Supported Living Flat	07/09/11	29/09/11	Withdrawn	Withdrawn
Carrie	Under 35	Provider 1	Married	With Husband in shared Supported Living house	Telephone	18/11/11	01/12/11	Not required
Joe	Under 35	Provider 1	Married	With Wife in shared Supported Living house	Telephone	18/11/11	01/12/11	Not required

Kerry and Dean, John and Caroline, Emma and Liam and Carrie and Joe interviewed together. Average length of interview-1 hour  
 Approximately 15 hours of interviews - couples interviewed in pairs (22 hours of Participants)



## **4.2 Forming Attachments - Barriers and Facilitators to Relationships**

The participants' stories were developed so readers could begin to understand what it is like to be an adult with a learning disability in a relationship. Van Manen's method was used to conduct an exploratory thematic analysis of the participant's stories. Max Van Manen (1990) stated that meaning within textual narrative was understood through the analysis of themes identified. However, he disliked traditional thematic analysis through the use of coding or a structured process. He believed that the identification of themes was achieved via the 'free act of seeing' (p.79).

The exploratory thematic analysis identified themes which acted as barriers or facilitators to forming relationships for the participants in this research. The main themes identified were: attachment, abandonment, abuse and autonomy/protection. Each theme will be discussed within the context of each participant's story.

### **4.2.1 Attachment**

#### **Alan**

The circumstances of Alan's childhood and early adulthood were not made explicit in the interview. He seemed to relish any opportunity to engage with others, suggesting a desire for attachment, and appeared to thrive on human company. From the interviews, it was unclear who Alan was attached to besides his wife. Alan's attachment appeared to focus on 'people' in general rather than specific individuals. Even his marriage was spoken about in terms of 'meeting people', meaning his wife's family. Alan mentioned a brother but no other members of his family were discussed in the interview. Alan had experienced living in large care homes with high numbers of staff and tenants who would often leave. I suspected that Alan had seen many people pass in and out of his life which could cause making attachments to individuals challenging. Perhaps Alan, like many people without a learning disability, saw his marriage as a way of securing himself to another and making an attachment.

#### **Kerry**

Kerry's abusive past suggested that she has lacked opportunities to feel love and experience secure attachment. During her childhood in care Kerry had numerous caregivers and it appeared unlikely that she would have formed a strong attachment to any specific individual as they changed too frequently. Kerry continued to live in large

care homes as an adult but felt sadness when staff that she was close to left, suggesting that she is able to form attachments. Some of her attachments seemed to be dysfunctional because she had had numerous sexual partners despite appearing unenthusiastic towards sex, suggesting she possibly used sex to secure affection and attachments with men. Kerry had been abused by various men in her life: it appeared she had no secure attachments to anyone except Dean as others had moved on, let her down or broke her trust. Excluding Dean, paid staff appeared to be the most constant influence in her life. Kerry was attached to Dean and able to trust him but not to the extent of overcoming her concerns regarding money and perhaps was defending herself from the possibility of being hurt again.

### **Dean**

Dean was raised by an adopted family with whom he remained close, visiting them with Kerry (it was not known how frequently) which suggests he felt attachment to them and possibly loved by them. Staff said he had had a 'difficult past and fabricated stories to compensate for this'. The true nature of his 'difficult past' was unknown. Dean had four children but he had no real relationship with them. It was unclear if his own childhood had influenced his role as a parent. His apparent lack of attachment to his children suggested that Dean may have had issues forming attachments, possibly due to a poor relationship with his 'pre-adoptive' primary caregiver. Dean wanted more children and may have seen fatherhood as an opportunity to form attachments, possibly believing he would have a different relationship with any subsequent children with Kerry due to their secure attachment to each other.

### **Caroline**

Caroline spoke of a real fondness for her father, often using the word 'special' for things he had for her, indicating that he had provided her with early life experiences of feeling loved and secure. There was warmth in her voice when describing him that was absent when discussing other family members. After he died when Caroline was still a child, she appears to have been rejected by her family and had no secure attachment to any living member. John had become her family as he was always present and would not leave her. She spoke about John in the same way she described her father: John made her feel special, unlike anyone else.

### **John**

John's childhood appeared to lack any secure attachments or recollections of feeling loved since he was unable to recall his own birth parents and grew up in a children's home until he was fostered by Mrs X. Despite living with Mrs X for many years John

still addressed her as 'Mrs'. This suggested that the relationship was maybe more formal than a 'foster parent'. John appeared more attached to her daughter whom he called his 'sister'. His attachment with her was important to him and he truly valued her involvement in his life. John loved his partner Caroline but it felt like he was slightly less invested in the relationship as, unlike Caroline, he had a 'sister' whom he loved and felt it was reciprocated. John appeared more attached to women as all the significant people in his life were women. This was perhaps due to a lack of male influence in his life.

### **Emma**

Prior to her illness and move into residential care Emma described her relationship with her family as very good. However, she was possibly over-attached to her parents, suggesting that she had been 'clingy', and she referred to wanting to 'spend all her time' with them. Liam had now 'replaced' her parents. Her need for company suggested Emma was insecure and fearful of being alone. It was unclear if the abuse Emma suffered had affected her in this way or if it pre-dated this. Despite this, Emma had a loving and supportive relationship with her family and it appeared that this enabled her to develop a loving and supportive relationship with Liam. Both Liam and Emma seemed secure in their love for each other, confident that the other loved them and wanted to be with them.

### **Liam**

Liam, like Emma, grew up in the family home with his younger sister. Liam described a close relationship with his mother but was less attached to his father. Liam was very open to discussing his emotions and appeared empathic. Liam stated he was keen to not be like his father in his parents' relationship. The loving and supportive relationships with his mother and sister appeared to have enabled him to develop a loving and supportive relationship with Emma.

### **Carrie**

Despite having such a large adoptive family, Carrie only had a close relationship with one sister and little contact with the others. She was very close to her mother and it was unclear what relationship Carrie had with her father, whom her mother had divorced. He attended her wedding and Carrie recalled her parents fighting as a child but that was her only mention of him. It appeared that Carrie came from a loving home but there were aspects of her personality which suggested some issues surrounding attachment around her apparent desire to be 'wanted' by others. This was indicated by her frequent mentioning of both men (and some women) who 'wanted her' romantically.

## **Mary**

Mary had lived with her family until her early forties. Despite loving them she did not enjoy visiting them, stating she did not get the attention she required as her father was caring for her sick mother. Mary suggested she felt neglected by them and her needs had not been met when she lived at home. Mary appeared to equate love with physical affection: her family provided this in the form of cuddles. This way of demonstrating 'love' was a pattern that she continued with her own partner. Mary suggested that physical availability was central to her emotional attachments as she said she loved Gary most as he visited her more frequently. This suggested her family were not available to her as she required.

## **Peter**

Peter said little about his family, with whom he has no contact. His stepmother desired no contact following his father's death and all other close family members had died. Peter had no relationship with his wife's family. With the exception of his wife, Peter had no relationships or attachments to others. This could have explained why he appeared fixated on his wife, refusing to expand his social circle. Peter's wife stated she wanted a separation during the course of the interviews. Peter seemed unable to comprehend that his wife may not choose to reconcile their relationship. For him, he may see this as his only chance to form an attachment with another person.

## **4.2.2 Abandonment**

### **Alan**

There was limited knowledge regarding Alan's family and it was unknown how he came to live in residential care and whose choice this was. Alan only suggested that feelings of abandonment centred around his wife, as she was no longer able to be his travel companion. Although unable to help this, there was a sense that she had 'let him down'. This was reflected in his statement about Ann not completing the physiotherapy exercises as required following the accident. Meeting people was important to Alan, which had previously been accomplished by frequent travelling, living in a large house with multiple tenants and socialising with his wife's parents. He now lived in a smaller house, travelled less and his wife's parents had passed away. It is possible that Alan felt abandoned by having fewer people to interact with. No specific individual was mentioned, but he referenced all the changes that happened in his life which lessened his social circle. He may have felt abandoned by circumstances.

### **Kerry**

Kerry experienced the ultimate abandonment where her mother failed to protect her from her abusive father and subsequently her stepfather, suggesting Kerry's mother chose her partners over the safety of her child. Kerry, rather than the abuser, was removed from the family and was placed in care. As a result, she experienced various caregivers throughout her childhood and felt sadness when staff who she was close to left. She may have felt abandoned by departing staff. However, a lifetime of these departures may also have hardened her to their impact. Perhaps Kerry no longer allowed herself to become as attached to staff as she had in her youth in order to lessen the sadness that she felt. This was suggested in her attitude and behaviour in the interview. Kerry appeared hostile at times, which suggested a defence mechanism which may have been developed to protect herself.

### **Dean**

Dean was placed into care as a child. The circumstances surrounding the placement were unknown, but he had an adoptive family. It was possible that Dean felt feelings of abandonment after being removed from his family and being placed up for adoption. However, this may have been lessened by his positive relationship with his adoptive family. Dean was keen to marry and start a family with Kerry. This was possibly a way of reducing the likelihood of her 'abandoning' him by terminating the relationship and possibly providing Dean with the additional security of marriage and parenthood.

### **Caroline**

Caroline was not placed in care but was sent to a boarding school by her mother. Her only warm memories of her childhood were when she was with her father. It was suggested that Caroline felt rejected by her mother who sent her away on multiple occasions, to boarding school, a convent and a care home. From her narrative it appeared there was no real relationship between them. Caroline was open about the rejection she felt: she had limited contact with her sisters and also felt rejected by them. Caroline did not feel part of her family. She was physically removed from the family and, when she was eventually placed in a situation where family contact was possible and encouraged, it was possibly too late. Caroline appeared to have lost the skills to re-engage with her family, finding it difficult to know when to contact them by phone. This suggested a double rejection, once by her family sending her away, and then a lack of contact, coupled with a loss of skills to re-engage with her family. To compensate, she had John who was always available to her and would not abandon her.

### **John**

John spent his childhood living in a children's home until he was fostered by Mrs X. He was placed back into care when Mrs X. became too ill to care for him. It was difficult to establish if John understood her illness as the cause of being placed in care or saw his removal as a rejection. John desired to live within a family unit again and it would be unlikely that he felt no feeling of abandonment when he was removed from this environment. John had no recollection of his birth parents and spent his life in care. It may have been possible that John had grown so familiar to a multiple caregiver environment that his thresholds for feeling abandoned or rejected were lower than most. John remained in contact with his 'sister' throughout his life, which perhaps lessened his feelings of rejection. Despite his past, John was able to develop and maintain a stable long-term relationship with Caroline.

### **Emma**

Despite coming from a loving a supportive family, Emma appeared to have felt abandoned and rejected by her family when she was unable to return home from hospital when she had wanted. Although Emma's move into residential care worked out well it was not her decision and she was unhappy about it. Emma stated that she understood later that her parents were acting in her best interests. This suggested that Emma was able to overcome her feelings of abandonment and, on reflection, knew her family loved her and would not act maliciously.

### **Liam**

Liam had a close relationship with his sister and mother but a poorer relationship with his father. Liam suggested he felt abandoned by his father at times as he could be rejecting either by physically sending Liam away or being emotionally unavailable due to his depression. Liam expressed his distress about when this had occurred. However, compared to his other family relationships and his relationship with Emma, his relationship with his father appeared to have less significance.

### **Carrie**

Carrie made no reference to any feelings of abandonment. She was adopted when she was a baby and spent most of her life living with her mother following her parents' divorce. Carrie was not explicit in saying this but it was possible that she felt some rejection from her mother when she had to move from the family home. Her mother became too unwell to care for her due to a terminal illness, but the impact of this rejection may have been minimised as Carrie appeared to understand the motivation behind this move. Carrie subsequently met Joe as a result of moving from home.

Carrie was possibly able to overcome any feelings of abandonment as, on reflection, she knew her mother loved her and was acting in her best interests.

### **Joe**

Joe appeared to come from a secure family and made no reference to any feelings of abandonment.

### **Mary**

Mary moved to her flat from her family home. It was unclear why she came to live there since she did not initiate the move. Despite this, Mary said she was content. She had more independence, freedom to have relationships, engaged in more activities and liked her staff and her environment. It was unknown if Mary had any feelings of abandonment at the time. She expressed a desire for her family to visit her more in her own home, suggesting she wanted the interactions with her family to be in an environment where there were no distractions to divert their attention from interacting with her. Mary did not necessarily feel abandoned by her family but possibly felt she required a better quality of interaction when she saw them.

### **Peter**

Peter has been rejected by almost every important person in his adult life except his parents and grandmother. He grew up with his parents, with whom he had a good relationship, and also had a good relationship with his grandmother. After his mother's death his father remarried and after his father's death his stepmother rejected Peter and desired no contact. Peter appeared to be in denial of this rejection. Peter's denial of the rejection appeared to continue when, during the interviews, his wife no longer desired to be in the relationship. Peter did not appear to know why all his relationships had broken down and this extended to his marriage. Perhaps Peter was aware but it was too difficult to admit, which would have made it appear more real. Peter's lack of discussion on these topics could be a defence mechanism to protect him from further pain. It is probable that these rejections have affected his enthusiasm for making new attachments to others and possibly explaining his small social circle and lack of engagement with others beyond the 'safe environment' of his house and housemates.

### **4.2.3 Abuse**

#### **Alan**

Alan did not disclose any experience of abuse in the interview. There was no evidence in his narrative which suggested any experience of abuse.

#### **Kerry**

Kerry had a traumatic abusive past. She suffered physical, sexual and psychological abuse from both her father and her stepfather. Kerry's childhood provided a negative experience, identifying men as abusers. This may have taught her that the people you love can hurt you. Kerry experienced further abuse in her adult relationships from partners who attempted to control her and demand her performance of sexual acts.

#### **Dean**

It was said by staff that Dean had a 'difficult past' and he was removed into care as a child. This suggested he may have experienced some form of abuse in childhood but this was not disclosed by Dean. Dean also had a relationship with Amanda (the mother of his children) with whom he defined as 'mentally unstable'. Dean claimed she was violent towards him and there was now a restraining order in place against her. Despite his childhood experiences and experience of an abusive partner Dean appeared willing and trusting of Kerry, wanting their relationship to progress to cohabitation, marriage and children. This suggested that despite a 'difficult past' Dean was able to overcome this and develop and maintain a positive relationship with Kerry.

#### **Caroline**

Caroline did not disclose any experience of abuse in the interview. However, the rejection she felt when her mother 'sent her away' could have been interpreted by Caroline as emotional abuse.

#### **John**

John experienced abuse from an ex-partner. John remained in this abusive relationship despite physical assaults and financial abuse until the person moved away. It was also unclear if John felt this was acceptable in relationships as he had no previous experience of being in one or witnessing any in his childhood (he predominantly grew up in institutions). Caroline claimed that John had mixed emotions about his ex-partner leaving which suggested that an abusive partner to him was better than no partner at all. Despite this, John was able to develop a non-abusive relationship with Caroline.



### **Emma**

Emma's experience of relationships prior to Liam was that they were abusive. One partner was controlling and exploitative and another committed a sexual assault (possibly rape) which resulted in Emma's decline in mental health and subsequent hospitalisation. Following these incidents Emma may have seen men as potential abusers and this could have affected her ability to trust in relationships. Emma could be considered courageous to have started a relationship with Liam considering her past experiences or Emma's parents' loving relationship may have provided a model to demonstrate that not all relationships followed this pattern. Emma's relationship with Liam was reparative as it enabled her to rebuild her trust in men and understand that not all men were abusers. Emma subsequently received psychological therapy. This, coupled with a supportive family background, may have enabled her to overcome the psychological trauma sustained from the abuse.

### **Liam**

Liam did not disclose any experience of abuse in his relationships. However, he did experience abuse from a housemate and members of the public. Liam lived with a housemate who intimidated him, but he was able to remove himself from the situation with the support of his family. Liam was also physically assaulted by a girl without a learning disability, most likely due to his learning disability.

### **Carrie**

Carrie claimed to have been 'almost raped' by an ex-partner. Carrie made other statements in the first interview which were deemed by Joe to be 'lies' and which had to be removed from the transcription at his and her request. Therefore, I was uncertain if this claim was true. However, Joe maintained that he witnessed the abuser's calls to the house and was present at the police interview. Carrie claimed that the abuse brought her and Joe closer together emotionally, which suggested that Carrie could find some positive outcomes from the experience despite the distress it caused her.

### **Joe**

Joe did not disclose any experience of abuse in the interview. There was no evidence in his narrative which suggested any experience of abuse.

### **Mary**

Mary did not disclose any experience of abuse in the interview. However, the staff claimed that her family financially abused her. It was unclear if Mary was unaware of this situation or chose not to disclose this. Staff stated that prior to her move to

supported accommodation her family may have used her benefits to supplement their income. Mary (and staff) acknowledged that her family loved her but possibly saw her as an opportunity to gain financially and did not see their actions as abusive.

### **Peter**

Peter did not disclose any experience of abuse in the interview. However, he did state that he did not have good relationships with his wife's family. Staff stated he had been verbally abused and physically threatened by them. It is probable that Peter's issues surrounding attachment would have been exacerbated by his abusive experiences with his partner's family.

## **4.2.4 Protection and Autonomy in Relation to Abuse**

### **Alan**

Alan did not disclose any experience of abuse in the interview.

### **Kerry**

Kerry experienced abuse in her childhood and her mother did not protect Kerry by removing her from the abusive situations by leaving her abusive partner and allowed the abuse experienced by Kerry to continue. This suggested Kerry learnt that no-one can keep you safe. Kerry also experienced abuse from ex-partners, however, unlike in her childhood, she was able to assert herself and terminate her dysfunctional relationships and go on to develop a reciprocal, non-abusive relationship with Dean.

### **Dean**

Dean was protected by the state from his family situation by being removed into care. However, the circumstances for his removal were unknown and it was unclear at what stage he was removed and why. Dean experienced abuse from an ex-partner and had the autonomy to report this to the police who provided protection in the form of a restraining order. It was unclear if he received support from staff or family in reporting the abuse to the police.

### **Caroline**

Caroline did not disclose any experiences of abuse. However, she did experience restrictions on her freedom and strict rules which governed aspects of her daily routine such as meals and daily schedules. Such measures were enforced by an external authority and were most likely implemented for protection but also possibly for control.

Caroline had an extensive vocabulary and had the ability to discuss abstract concepts. However, she appeared younger than her chronological age and lacking in self-confidence. This suggested that her experience of being subjected to imposed rules and structure in boarding schools, convents and strict religious care homes may have impacted on her development, her ability to make choices for herself and develop autonomous thought. It could be argued that these restrictions may have had a longer lasting impact than any experience of abuse.

### **John**

John experienced abuse from an ex-partner and had alerted the staff to the abuse but, according to him, they provided no support in terminating the relationship or addressing the issue. This may have taught John that no-one can keep you safe from abuse or will assist you to resolve relationship difficulties. John was abused initially by the ex-partner but also by the negligent staff who did nothing to support him. However, John was able to overcome this experience and develop a non-abusive relationship with Caroline. This was possibly due to the good relationship support he subsequently received from his current provider.

### **Emma**

Emma was protected by staff when dealing with a controlling and demanding ex-partner. Staff intervened by informing his staff of the situation and intercepting his telephone calls to Emma. It was unclear if Emma was able to assert her autonomy and would have been able to do this or if her staff felt obligated to do this due to her past experiences, but they encouraged Emma to be autonomous when she began dating Liam by reinforcing that she did not have to engage in sexual acts that she felt uncomfortable with and providing emotional support to her in the early stages of the relationship.

### **Liam**

Liam was supported in being autonomous by his family when he was assaulted by a girl without a learning disability: his father supported him in contacting the police and he was able to report the incidents. Despite his experiences Liam appeared a confident young man and he continued to travel and socialise independently. It was possible that the support provided by his family may have lessened the impact of the abuse.

### **Carrie**

Carrie had experienced abuse from an ex-partner and she felt that Joe's support, such as confronting the abuser when he called the house, made her feel protected against

further abuse. Also, Joe's support during the police interview allowed her to assert her autonomy by reporting the abuse she experienced, claiming he was her 'rock' throughout this process.

### **Joe**

Joe did not disclose any experience of abuse in the interview.

### **Mary**

Staff stated that Mary was financially abused by her family so to protect her she was no longer allowed to take large sums of money home as requested by her family. It was unclear if she saw her family less frequently as a result of staff restrictions when safeguarding her money. Staff explained that Mary lacked the autonomy to make this decision and they had to act in her best interests to protect her assets.

### **Peter**

Peter had been abused by his wife's family. Due to this, staff no longer allowed them access to the property and Peter, thus protecting Peter from further abuse.

The accounts presented in Section 4.2 could be explained through attachment theory as showing examples of the positive or negative influence of the primary care givers (or those with similar characteristics to the primary caregivers in adulthood such as staff), considering how their influence may have acted as barriers or facilitators to relationships.

## **4.3 Participants' Stories in relation to Maslow's Theory**

Section 4.2 examined participants' stories in reference to attachment theory; this Section will re-examine them in relation to Maslow's theory. Maslow stated that individuals who failed to have their 'basic needs' of the hierarchy of needs met (Figure 1A) would fail to attain higher levels. The 'basic needs' include 'physiological needs' and 'safety and security needs' and 'higher psychological needs' include 'love and belonging' and 'self- esteem'. There was evidence which implied that not all participants had attained their 'safety and security needs', yet most appeared to have good attachments with a partner which potentially satisfied their 'love and belonging needs'.

### **Alan**

Alan's description of marriage did not appear based in love and intimacy as defined by attachment theory but reflected Maslow's historical view of marriage, linking it to

security and social status. For Alan, this may have been the security of having companionship and holding the socially valued role of a husband. Alan appeared to have enjoyed the sense of 'belonging' he felt in regards to his wife's parents who have since passed away. This suggested his 'love and belonging needs' were not fully met. However Alan appeared a confident man and spoke proudly of his employment and role as a husband. This suggested that Alan may have attained the penultimate level in the hierarchy, 'self-esteem needs', regardless of whether his lower level needs had been met.

### **Kerry**

Kerry had experienced multiple instances of abuse where her primary caregiver did not meet her 'safety and security needs' or, on occasions, her 'physiological needs' such as food. However, she was able to overcome this to form a loving relationship with Dean. It could be argued that since her childhood experiences, Kerry appeared mainly responsible for meeting her own 'safety and security needs', for example by terminating abusive relationships. Her self-reliance possibly increased her ability to meet her 'self-esteem needs'. Dean has since been able to meet some of Kerry's 'safety and security needs', by helping her on public transport and providing emotional support. This implied that she was reducing her self-reliance and increasing her ability to meet her 'love and belonging needs' by placing trust in Dean.

### **Dean**

Little was known about Dean's childhood other than it was described as 'difficult' by the gatekeepers and he was adopted, possibly implying that his 'safety and security needs' were unmet prior to his adoption. The love of his adopted family may have assisted in rectifying this to some extent. Dean had relationships with numerous women prior to Kerry but it appeared that only their relationship went some way to fulfil his 'love and belonging needs' as Dean defined their relationship as the only one he had committed to. It appeared that Dean's role as a father was limited in its contribution to meeting his 'love and belonging needs' as he had little contact with his children. Despite this, he wanted to start a family with Kerry. It was possible that his unmet 'love and belonging needs', and a possible lack of secure attachments in childhood, acted as a 'driver' to have more children and also a possible way of ensuring Kerry's continued commitment to him.

### **Caroline**

Caroline felt rejected by her family yet her 'physiological needs' and 'safety and security needs' appeared to have been met within childhood. It could also be inferred that her

'love and belonging needs' were met by her father, which possibly enabled her to love and feel loved by John. This implies that possibly one loving caregiver was sufficient to enable people to meet their 'love and belonging needs'. Based on her presentation in interviews, Caroline appeared to lack self-confidence. This possibly related to the rejection she felt regarding her family. Despite being in a loving relationship with John, her restrictive childhood and early adulthood could have limited her potential to 'self-actualise' and limited her to experience life as a lower level. Caroline desired marriage, and like Maslow, linked it to social status. Marriage was possibly perceived as a way to increase her confidence and self-respect and may have enabled her to fulfil some element of her 'self-esteem needs'.

### **John**

Based on research presented in Section 2.3.5, John may not have had his 'safety and security needs' met due to growing up in institutional care. However, he appeared able to form a loving relationship with his foster sister. This implied that, according to Maslow's theory, the loving caregiver could be an older sibling. John experienced further threats to his 'safety and security needs' when an ex-partner was abusive and no-one stepped in to protect him. Despite this, he appeared able to meet his 'love and belonging needs' and develop a loving relationship with Caroline.

### **Emma**

Emma appeared to have had her 'physiological needs', 'safety and security needs' and 'love and belonging needs' met in childhood as a result of a supportive loving family. According to Maslow (1943), this would be what enabled her to overcome her subsequent abuse and develop loving relationship with Liam. Emma was keen to become Liam's wife, however her desire for marriage appeared to be focused on love rather than increasing social status. Staff had supported Emma in terminating an unhappy prior relationship, possibly increasing her 'self-esteem needs' by increasing her self-respect and confidence.

### **Liam**

Liam appeared to have had his 'physiological needs', 'safety and security needs' and 'love and belonging needs' met in childhood as a result of a supportive loving mother and sister. Despite experiencing threats to his 'safety and security needs' in adulthood, Liam appeared a confident young man, and felt assured that he would cope well living with Emma outside of a group environment. This confidence possibly indicated that he had met his 'self-esteem needs', which may have been due to the support he had from his staff and family to address issues from the abuse he suffered, thereby increasing

his confidence and self-respect. Like Emma, Liam's desire for marriage appeared centred on love rather than increasing social status.

### **Carrie**

Carrie had experienced abuse. Her parents had a difficult divorce and she was adopted, these events provide a possible indication that her 'safety and belonging needs' may not have been fully met. Despite this, she was able to form a loving relationship with Joe. Carrie was married to Joe, and being a wife was considered a socially valued role by Maslow which could have assisted her to reach the penultimate level of Maslow's pyramid 'self-esteem needs'. However, Carrie displayed behaviours which could have been considered 'attention seeking', possibly implying she was not self-confident and this impacted her ability to attain the 'self-esteem needs' level. Carrie's decision to marry Joe appeared related to love rather than increasing her social status.

### **Joe**

Joe appeared to have had his 'physiological needs', 'safety and security needs' and his 'love and belonging needs' met in childhood as a result of a supportive loving family. Joe appeared secure and confident. It appeared that he had not experienced any threats to his 'safety and belonging needs', was married to a woman he loved, had friends both with and without learning disabilities and had a job he enjoyed. Joe appeared to have reached the 'self-esteem needs' level of Maslow's hierarchy. It did not appear that he had 'self-actualised' as he still desired to live alone with his wife and, for whatever reason, this had not happened.

### **Mary**

Mary appeared to have had her 'physiological needs' met by her family; however there were issues surrounding her 'safety and security needs' in regards to the safety of her money as staff claimed her family misused this, although it was unclear how aware Mary was of the threat to her finances. Mary did not choose to move and this possibly impacted on her 'love and belonging needs' in relation to the possible rejection she felt from her family. Mary's move increased her autonomy to engage in intimate relationships, which possibly had a positive impact on her 'self-esteem needs'. Despite her family's threats to her 'safety and security needs' in relation to finances, Mary loved and felt loved by her family, and this appeared to fulfil her 'love and belonging needs'. She was able to develop a loving relationship with Gary. Due to the embodied reality of her learning disability and resulting support needs, it would have possibly been unrealistic for her to fully attain some higher 'self-esteem needs' of the pyramid such as

autonomy.

### **Peter**

Peter claimed to have experienced a loving childhood which possibly enabled him to develop a loving relationship with his wife. However, his experiences of abuse may have stopped him attaining some aspects of the 'higher psychological levels' such as close friendships to meet his 'love and belonging needs' due to his possible fear of abuse from others and in a possible attempt to protect his 'safety and security needs'. Peter was in the socially valued role of a husband which may have increased his 'self-esteem needs'. However, due to the embodied reality of his learning disability and resulting support needs, it may have been unrealistic for him to fully attain the 'self-esteem needs' of the pyramid.

Table 7 identifies the challenges faced by participants in their daily lives.

Table 8 includes statements which highlight how the key challenges faced by participants were experienced by individuals. Their statements were divided into four themes which were identified within the exploratory thematic analysis. Each statement summarises how each theme was represented in the different participants' stories. The final column displays a summary of how the participants' themes related to Maslow's theory.



**Table 7- Challenges faced by the Participants**

Name	Age	Mental Health Issues	Poverty (lack of full-time Employment)	Sexual Abuse	Physical Abuse	Other Abuse Psychological / financial	Parental Divorce/ Death of Parent in childhood	Experience of care/ institutions as a child	Physical Disability/ill Health including speech impairments	Ethnic Minority
Alan	60 +		✓				unknown	unknown	✓	
Kerry	Under 35		✓	✓	✓	✓	✓	✓	✓	
Dean	Under 35		✓		✓			✓		
Caroline	35-60	Possible depression	✓			Possible psychological abuse by rejection	✓	✓ (boarding school)		
John	35-60		✓		✓	✓		✓	✓	
Emma	Under 35	✓	✓	✓	✓	✓				
Liam	Under 35		✓		✓	✓	✓		✓	
Mary	35-60		✓			✓				✓
Peter	35-60		✓			✓	✓		✓	
Carrie	Under 35		✓	✓			✓			
Joe	Under 35		✓							

**Table 8: Main Themes Identified in the Participants Stories**

<b>Name</b>	<b>Attachment</b>	<b>Abandonment</b>	<b>Abuse</b>	<b>Protection/ Autonomy</b>	<b>Maslow's Hierarchy</b>
Alan	Attachments can be fleeting, making it important to interact with people to ensure you have sufficient opportunities to develop attachments with others	It is possible to feel abandoned even if the person is still there if they can no longer perform the same function in your life	Alan had no experiences that he disclosed	Alan had no experiences that he disclosed	Supports Maslow's historical view of marriage as a means of affording security and increased social status
Kerry	Sex is a way of attaching people to you.	Nothing is permanent, care homes change and carers leave you, making it hard to let people close.	People who you are close to can abuse you and not keep you safe, making it hard to trust people	People, even mothers, do not protect you from abuse	It is possible to experience serious deficits in the lower levels of the hierarchy and still meet your 'love and belonging needs' with a partner
Dean	A difficult childhood may have an impact on how you relate to your own children	A loving adoptive family can enable a person to overcome a troubled relationship with a birth family	Despite a 'difficult past' or an abusive relationship it is possible to develop a trusting relationship with another person	Statutory organisations such as social services or the police can protect you from abuse	Positive family relationships after traumatic events can help overcome deficits to 'safety and security needs' which enabled people to fulfil their 'love and belonging needs' in adulthood

<b>Name</b>	<b>Attachment</b>	<b>Abandonment</b>	<b>Abuse</b>	<b>Protection/ Autonomy</b>	<b>Maslow's Hierarchy</b>
Caroline	Being loved is being made to feel important, special and included by another person	Being sent away from the family and then rejected again when reunited was a double rejection	Rejection can be as damaging emotionally as abuse	Restrictions may have had a more lasting impact on development than an experience of abuse.	Marriage is desirable to increase social status. 'Self-esteem needs' can be limited by restrictive staff practice.
John	You do not need to have an entire family to feel loved and wanted just one person is enough if they make you feel this way	Growing up in a multiple care -giver environment may decrease thresholds for feeling abandoned, but maintaining contact may lessen feelings of rejection.	It can be difficult to know what a good relationship is if you have never witnessed any or had support to develop one.	No-one can keep you safe from abuse or will assist you to resolve relationship difficulties	Loving siblings can meet 'love and belonging needs' which enabled people to develop a relationship with a partner
Emma	Witnessing a loving parental relationship (both as a couple and as parents) can enable a person to overcome abuse and continue to develop a positive intimate relationship of their own.	It is possible to overcome feelings of abandonment if you are secure in the love of your family and know they would not act maliciously.	A circle of support from family, professionals and partners can be effective in enabling a person to overcome trauma and go on to develop a non-abusive relationship	Staff can protect you from abuse but also help you to develop your own autonomy	Marriage was not seen as a way to increase social status but rooted in love and intimacy. Threats to 'safety and security needs' could be overcome if 'love and belonging needs' were secure due to a loving family and good staff.

<b>Name</b>	<b>Attachment</b>	<b>Abandonment</b>	<b>Abuse</b>	<b>Protection/ Autonomy</b>	<b>Maslow's Hierarchy</b>
Liam	Parental characteristics can have a significant impact on an individual's personality and how they interact within their own relationships	A full life and other secure relationships can reduce feelings of rejection from a parent	People with a learning disability are more likely to be targeted by abuse	Good support can reduce the lasting impact of abuse and help develop autonomy and confidence.	Marriage was not seen as a way to increase social status but rooted in love and intimacy. Threats to 'safety and security' could be positive if addressing them increased autonomy and 'self-esteem needs'.
Carrie	The desire to be wanted or needed does not diminish even when in a secure and loving relationship.	It is possible to overcome feelings of abandonment if you are secure in the love of your mother and know she would not act maliciously	Abuse can be seen in a positive light if it helps a couple to come closer emotionally	A partner can protect you from future abuse and provide emotional support to overcome it	Issues to 'safety and security needs' can impact on a person's ability to fulfil their 'self-esteem needs' even if their 'love and belonging needs' were met.
Joe	Positive relationships within your extended family assist individuals to develop to be secure and confident within their own lives and relationships.	Joe had no experiences that he disclosed	Joe had no experiences that he disclosed	It is possible to protect my wife from some abuse and to lessen its impact by providing emotional support	People who experience no threats to their 'basic needs' appear to attain the higher levels of the hierarchy with relative ease

<b>Name</b>	<b>Attachment</b>	<b>Abandonment</b>	<b>Abuse</b>	<b>Protection/ Autonomy</b>	<b>Maslow's Hierarchy</b>
Mary	Being available physically (in terms of affection and availability) is important for attachment.	It is the quality of the interactions not the frequency that alleviates feelings of abandonment	Those closest to you can be abusive even if they do not mean to cause lasting harm	Staff can protect you if you do not have the autonomy to do this yourself	Living outside the family home can increase 'self-esteem needs'. The embodied reality of having a learning disability can impact what is possible in terms of attaining higher levels within the hierarchy
Peter	A lack of attachment within the family can have an effect on your ability to make healthy relationships with others as an adult.	Rejections from significant people in your life can affect your confidence in making new relationships	All relationships have the potential to become abusive if there is no-one to protect you	Staff can put measures in place which can help you remain safer from abuse.	Deficits within the 'safety and security needs' can impact on a person's openness to explore new relationships

#### 4.4 Summary of Exploratory Thematic Analysis

The exploratory thematic analysis in Section 4.2 and 4.3 identified that participants faced many barriers to the formation of relationships. These included abandonment, rejection and abuse. Maslow's theory (1943) advocated that such barriers impacted on an individual's ability to attain the lower levels of the hierarchy such as 'safety and security needs'. According to the 'hierarchy of needs', individuals whose 'safety and security needs' remain unmet would be unable to attain 'higher psychological levels' such as 'love and belonging needs'. Attachment theory presents a similar view, arguing that individuals who experienced insecure attachments in childhood fail to develop loving adult relationships (Bowlby, 1979). However, the findings revealed that participants were able to overcome such barriers and engage in loving relationships. Families played an integral role in this and the findings suggested that, as proposed by attachment theory (Bowlby, 1979), the quality of the family relationship had a significant impact on the development of the participant and their relationships.

All significant rejections and abandonment experienced by the participants related to families. Seven participants had experienced a breakdown in the family unit, either by the death of a parent, divorce or experience of the care system/ institutions in childhood. The rejections were separated into two groups: those outside of families' control such as death, and the others were active choices to send participants away to a new home/institution or as a result of poor parenting forcing their removal. As supported by the concepts outlined in attachment theory (Ainsworth *et al*, 1978), participants' ability to overcome the rejections and abandonment was dependent on the quality of the relationship with their parents. Participants who had good relationships with one or both parents appeared either able to appreciate the reasons behind their rejections, such as acting in their benefit, or they had a good relationship with one parent making the other's rejection less damaging. Participants with poor relationships with their family possibly experienced greater abandonment and this rejection often extended beyond their parents to siblings and other relationships such as friendships. This suggests that poor family relationships can lead to issues surrounding making attachments with others and that rejection from families impacted on confidence and self-esteem. Maslow's theory (1943) made no link between the quality of parental relationships and subsequent effect on relationships with a partner, unless it specifically related to a deficit in their 'safety and security needs'. It was possible for participants to have had minimal issues regarding their 'safety and security needs' yet have a poor relationship with a parent (such as Caroline who claimed to have had a poor relationship with her mother).

Participants' stories indicated that some individuals had fewer opportunities to form secure attachments and to feel loved than other adults, but their learning disability did not appear to be a causative factor preventing them from forming meaningful relationships. Almost all of the participants had experienced situations where they had felt abandoned or rejected; this rejection originated from the main care giver. Unlike attachment, it was their learning disabilities, in most cases, which appeared to be a causative factor in their rejection. This was because, due to their support needs, they were more likely to have to move from the family home into supported accommodation and this appeared to happen outside of their control. People also appeared more likely to be placed into care/adoption, which may have been due to their disability. Like many people with a learning disability, over half of the participants suffered with some form of additional physical disability or medical condition which significantly impacted on their lives, such as diabetes, visual impairments or poor mental health and this could have impacted on their ability to remain within the family home. According to Maslow's theory this implied that participants frequently experienced deficits in meeting their 'physiological needs' due to poor health. Also the embodied reality of their learning disability imposed limitations on their ability to attain their 'safety and security needs' without support from staff, such as safeguarding their money and understanding risk. This had a further impact on their ability to meet their 'self-esteem needs'; some participants lacked the ability to be autonomous and make decisions independently such as moving into care.

Overall, their stories suggested that people with a learning disability are more likely to be victims of abuse, therefore experiencing more difficulty attaining their 'safety and security needs'. Eight participants had experienced some form of abuse, including physical, psychological, sexual or financial abuse. The abuse was perpetrated by both those with and without a learning disability. Abuse perpetrated by a member of the public was always by a person without a learning disability targeting a vulnerable person. There was a difference in the types of abuse experienced based on the gender of the participant. Three female participants had experienced sexual/attempted sexual abuse. Abuse occurring within a relationship was perpetrated almost exclusively by another person with a learning disability. Only one participant had experienced sexual abuse where the perpetrator did not have a learning disability (to our knowledge). Attachment theory argued that participants who experience abuse in childhood would experience difficulty forming relationships (Browne and Finkelhar, 1986) and Maslow (1943) agreed with this position. However, despite their experiences of abuse, this did not appear to prevent participants from developing meaningful relationships. Families played a key role in supporting individuals in overcoming abuse: those who had

supportive families appeared less affected by the abuse they suffered. Cases where the abuse was perpetrated by a family member appeared to have a great impact on participants.

Staff, families and statutory organisations such as Social Services and the police played a key role in protecting participants from abuse (ensuring their 'safety and security needs' were met). Unsurprisingly, due to the high levels of abuse experienced by participants and the legal requirement of duty of care, some staff and families were protective towards them. Protection included tactics such as managing a person's money to stop financial abuse or confronting abusers or their staff directly. Where families or staff did not intervene when they knew abuse was occurring this served as a second form of abuse and suggested to individuals that no one can protect them. Despite the damaging effects of abuse some participants were empowered to deal with abusive situations by staff, family or partners and were able to stop the abuse themselves or had the courage to report to the police. There were examples of staff providing emotional support and advice to participants which increased their autonomy and self-worth within relationships thus minimising the likelihood of further abuse and possibly increasing their 'self-esteem needs'. There was little evidence to support Maslow's claim that those who have met their 'love and belonging needs' ascended the hierarchy. Based on the challenges participants experienced and continue to face, including the embodied reality of their learning disability, it could be interpreted that they had not fully reached 'self-actualisation'.

Attachment theory, unlike Maslow's theory, professes love is a 'basic need'. Participants' ability to form a secure attachment despite significant challenges demonstrated the significance and healing power of love and supportive relationships. This implies that 'love and belonging needs' are possibly more significant than some aspects of 'security and safety needs', such as security of employment or wealth, and higher 'self-esteem needs', such as recognition and social status.

Chapter 5 will explore how these barriers and facilitators interact to form relationships for participants by applying Max Van Manen's hermeneutic phenomenological reflection to the findings from participant interviews and their resulting texts in the form of interview transcripts. The findings will be examined in light of Maslow's theory (1943) and attachment theory.



## Chapter 5- Need and Attachments: Forming the Relationships

Chapter 4, titled 'Setting the Scene', identified the barriers and facilitators to the development of the participants' relationships in relation to attachment theory and Maslow's theory (1943). This Chapter explores how these barriers and facilitators interact to form relationships for participants. It was these barriers and facilitators which appear central in determining what type of the relationship participants engaged in and what they look for in a partner/relationship.

The Chapter focuses on presenting my interpretation of the findings using Max Van Manen's hermeneutic phenomenological reflection outlined in *Researching Lived Experience* (1990) to analyse the texts, expanding on the themes identified in the previous Chapter and also the transcripts and audio recordings of the interviews, interviewer notes and the reflective diary as discussed in Chapter 3. This was undertaken to answer the research questions which were: what do people with learning disabilities look for in a potential partner and how do their prior experiences affect their choices and influence the relationships they experience?

Four main themes were identified from the field work and each theme also consisted of smaller related sub-themes. Each theme and corresponding sub-themes was explored separately. The four main themes are:

- Partner Selection
- Sexual and Physical Relationships
- Influence of Staff/Group Living
- Societal and Familial influences on Relationships.

The interaction between the four themes and corresponding sub-themes raised two key questions:

- What brings people with learning disabilities together and holds them together?
- What stops people with learning disabilities getting together or staying together?

This Chapter aims to discuss and explore these two questions in the context of the four main themes and corresponding sub-themes.

## 5.1 Theme One: Partner Selection

The first theme identified from the participants and their stories was partner selection and the factors which influenced their decision. There were three sub-themes which were significant in the participants' choice of partner which include:

Meeting potential partners

Attraction

Companionship

### 5.1.1 Sub-theme One: Meeting potential partners

#### Historical lack of opportunity to meet and mix

There was a difference relating to the ages of participants at the commencement of relationships for those over thirty five years old compared to younger participants (under thirty five years old). All of the older participants (over thirty five years old) met their partners later in life with no prior experience of relationships. All of the older participants had met their partner within the last ten years. This was possibly due to the historic segregation of the sexes within service provision for this group which could have contributed to the lack of relationships in their younger lives and will be considered further in Chapter 6.

Despite starting relationships later in life, some older couples still seemed to have had the experiences which were comparable to other younger people with their 'first love'. Caroline and John's relationship started in a way that was reminiscent in its innocence of teenagers, despite them being in their forties. Considering the time that had elapsed since their initial flirtation, the story was told by both Caroline and John with the enthusiasm and emotion of a couple still in love.

*Caroline: We got into the camper van, you were sitting behind or in front of me we just held hands and that's how it started. We were really, really in love.*

Both Mary and Peter met their first partners in their forties. Mary met her partner Gary at a local college for adults with learning disabilities. Prior to this Mary lived in her family home and it was not clear what opportunities she had to engage with others. Peter met his wife at a day service for people with learning disabilities. Neither Peter nor Mary had had any previous partners and were unable to explain why. It seems the environments where older participants met their potential partners were not typical compared to adults without a learning disability. It would be unlikely that adults over the

age of forty would still attend a local college, move into a shared group home with other adults or attend a day services. With the exception of day services the other environments would be more typical of younger adults without a learning disability such as university students.

### **Opportunities for interaction/ service provision**

All of the younger couples had prior experiences of relationships before their current one. In recent decades there has been a major shift in service provision to more 'single person services/community support', more mixing between sexes in local schools and colleges and increased participation in the community. Their exposure and engagement with the opposite sex outside the home of the younger group appeared greater than the older participants. These participants went to a mixed sex school and their experiences appeared similar to the relationships of young people without learning disabilities, such as kissing behind the bike sheds.

*Emma: I've heard it all before that. People used to do that in our school, go behind the bike shed.*

Despite this, to my knowledge, all of the participants had only experienced relationships with other people diagnosed with a learning disability, lived with other people who had learning disabilities and met partners in locations where only people with a learning disability congregated. Kerry and Dean were the exception to this, having met in a shop where Kerry worked. Both had the smallest support packages from staff and lived in individual flats (not part of a staffed block).

The high number of couples who began relationships within their homes suggested that, despite advances to integrate people with learning disabilities into mainstream society, a smaller insular society still remains with the inside of people's homes acting like a micro social world unopened to the wider world. Even younger couples' relationships began in the home after initial meetings in colleges/schools. Liam and Emma met at their sixth form college (for people with learning disabilities) but began their relationship when Liam came to view a room in a care home where Emma lived.

*Liam: When I went to try out a new house and Emma tried out new house and I asked her out and like I asked if her if she wanted to go out with me.*

Carrie and Joe's story was comparable to that of Liam and Emma: they had a shared experience of meeting at school and rekindling the relationship when Joe moved into a

shared supported living house in which Carrie already resided.

Peter and Mary, unlike all of the other participants, faced the additional challenge of being unable to go out without support, suggesting they had limited opportunities to meet people unaccompanied by staff. Peter stated that he sometimes wanted to access the community unsupported.

*Researcher: Do you mind that when you go out as a couple and they come with you?*

*Peter: No not always, not all the time.*

*Researcher: Would you like some privacy from the staff?*

*Peter: Sometimes*

In summary, the findings suggested that living in a group environment (a supporting living service or a care home) and attending social clubs/colleges specifically for adults with learning disabilities were facilitators for couples to develop relationships, but only with other adults with learning disabilities. It was suggested that these environments provided participants with an existing 'social circle' and access to potential partners. However, this was a barrier to the forming of relationships with people without learning disabilities due to segregation of their activities. Having a learning disability itself could be a facilitator in relationships, giving participants a shared identity and history which could have increased their feelings of intimacy. Older participants possibly experienced barriers to relationships in their past (evidenced by their lack of previous relationships). However, due to changes in attitude, this no longer appeared the case. Younger adults, who were more engaged in their local communities than older adults, still appeared to begin their relationships with partners met in these 'segregated environments' with the exception of Kerry and Dean. Staff presence could be a potential barrier to forming relationships. Staff have a duty of care to uphold participants' 'safety and security needs' at the possible expense of their privacy. This could impact on individuals' 'self-esteem needs' making it challenging to be respected by others when viewed as unable to function independently.

### **5.1.2 Sub-theme Two: Attraction**

#### **Physical Attractiveness**

Physical attraction was important to some participants but it did not appear to be the most important aspect of the relationship. For some participants (Dean, John, Caroline, Carrie, Joe, Emma and Liam) it was their physical appearance which first attracted

them to their partner but as their feelings progressed a stronger emotional bond developed. Mary valued Gary's physical appearance but it was not possible to ascertain what initially attracted her to Gary due to her limited verbal skills. Alan appeared to have difficulty stating what he found attractive about his wife. Alan valued her companionship (which is discussed in 5.1.3) but it was unclear from his description if it had to be 'Ann' in that role or could it have been any other female. Alan's love for Ann appeared to be more platonic than that of husband and wife: he was the only participant not to suggest a romantic/sexual element to the relationship. This implied that not all of the participants considered sex a basic 'physiological need'. It was possible he felt embarrassed discussing this with a female. With prompting, he was able to say he liked Ann as she was always smiling.

Peter, like Alan, was less forthcoming when asked what he found physically attractive about his wife. He thought she looked most beautiful on their wedding day. He said (with prompting) that he was attracted to her body, although this did not seem important.

*Peter: I say, she is actually pretty*

All of the younger participants, with the exception of Kerry, appeared to value and were more open in discussing what they found physically attractive about their partner. Kerry appeared uninterested in Dean's physical appearance and stated this played no role in selecting him as a partner. She repeated that there was no physical attribute of Dean's she valued above others. Dean openly shared that he was sexually attracted to Kerry.

The younger participants have grown up under a different political and social care system to older participants, with minimal or no experience of institutions, a greater involvement in the wider community and, as discussed in Section 2.2, with a more sexualised media/ society. Therefore, it was expected that they would be more open when discussing attraction, although some older participants were enthusiastic about discussing physical attraction. Caroline and John were equally as open about the physical attraction they felt for each other at the start of their relationship. Both found the other person 'good looking'.

*John: Good looking (Caroline)*

*Caroline: The same really, he looked good looking and everything, so, yeah. His eyes and his smile*

However, when asked what John found attractive he said 'tall women' and Caroline was not tall. The impact of this comment for Caroline was not discussed in the interview, but it could be possible to infer that this may have impacted on her negatively due to her experiences of rejection from her family (discussed in Chapter 4).

Mary, who was another older participant, was open about her attraction to Gary and favoured some non-traditionally attractive aspects of Gary's appearance, such as his shortness: perhaps this was due to her short stature. She also found his strength appealing.

*Mary: He's a strong man*

Carrie and Joe shared physical attraction and were the only couple to use sexualised language to describe their attraction to each other (despite not engaging in a full sexual relationship).

*Joe: Her face and her lips. You looked so hot (to Carrie).*

Emma, despite being in a sexual relationship, used less adult language in describing her attraction to Liam. It was his physical appearance that attracted her to him.

*Emma: I just liked the look of him. He was cute and sweet and lovely (laughs)*

Their relationship was initially based purely on a physical attraction which developed further. In interviews, Liam expressed his mutual physical attraction for Emma.

*Liam: Beautiful, actually (points at Emma).*

There was some degree of prejudice among participants: outward indicators of disability were seen as unattractive or described negatively by some participants. This included the use of wheelchairs, breathing equipment or having Down's Syndrome. This implied that possessing such attributes could be detrimental in attaining 'love and belonging needs' as this was considered unattractive in a potential partner. Such attributes may increase feelings of stigma reported by people with learning disabilities which could be detrimental to attaining social status and therefore their 'self-esteem needs'.

*Liam: She (an ex-girlfriend) can walk but not well. Too much, dancing for her, too much. She got a breathing mask. Went to her bedroom and she has a breathing mask and I thought 'no thanks'.*

*Mary: I don't like wheelchairs. I am ok, I am.*

Considering the abuse, abandonment and rejection participants had experienced (see Chapter 4) having a special person who appreciated their physical appearance could have been reparative to participants. It could have enabled them to achieve the 'higher psychological needs' of Maslow's hierarchy such as 'love and belonging needs' and 'self-esteem needs' by increasing their confidence and feeling respected and desired by others.

### **A 'Nice' Personality**

An appealing personality was a facilitator for relationships. Both Carrie and Joe agreed with this and identified similar aspects that they admired about their partner's personality

*Joe: She's a great person in my life, friendly, kind, funny and fun to be with. I love you so much. So happy about the person I am married to, and also, she is my soul mate.*

*Carrie: I am happy to feel like a girl, I am happy he is a lovely person. And I am always bubbly. He brings it out in me.*

Peter's description of his relationship with his wife suggested a connection that went beyond a mere physical attraction. Peter wore a locket which contained his wife's photo: his face broke into a smile when showing this to me. Peter's comments implied that his wife was an important person in his life for whom he cared deeply. Peter was more forthcoming about the aspects of her personality he admired rather than her physical attributes.

*Researcher: Peter what do you think life would be like without your wife?*

*Peter: I would actually miss her. I would actually cry.....She is actually nice.*

It was also important to Mary that Gary was 'nice' and this was reinforced by her throughout her statements in the interview. Regardless of age and gender, 'niceness' was the most highly valued trait. Both Caroline and John shared this opinion on what is important in a potential partner.

*John- Nice, kind and gentle (traits valued in a partner).*

*Caroline- I would want them to be friendly and I would want them to be friendly and things like that if it was possible, so yeah, friendly*

Emma compared how Liam had a different personality to her other abusive partners: he was more caring, sensitive and supportive towards her.

*Emma: He [Liam] is not the same as the other boyfriends. He is kind and gentle, lovely and caring.*

In summary, a partner's physical attractiveness appeared to be a facilitator in the formation of the relationship as it was what attracted most participants to their partner and this attraction developed into a deeper emotional connection. Despite it being an important factor in the formation of the relationship few participants had a predefined set of physical attributes that they desired in a potential partner and therefore appeared more open to what an 'attractive partner' was. Despite this 'openness' any outwards sign of disability (such as the use of a wheelchair) could be a potential barrier to the formation of relationships for some. The 'physical appearance of being a person with a learning disability' was not discussed by any participant and it was possible to determine that some participants had a learning disability from their appearance. However, this appeared to have no impact in the development of their relationships or partner choice. Almost all of the participants expressed a desire for a 'nice' partner (also encompassing traits such as friendly, kind, gentle), suggesting they wanted to be loved and special to someone. The traits described appeared similar to the secure attachment figure as described in Section 2.3.5. This was unsurprising when considering the physical, psychological and sexual abuse some of the participants had experienced, making niceness potentially more appealing (as discussed in Chapter 4). Participants were rejecting of partners who possessed traits which were detrimental to their 'safety and security needs' such as aggression. All of the participants stated that an appealing personality was more important to them than physical appearance in a relationship and in the selection of a partner.

### **5.1.3 Sub-theme Three: Companionship**

#### **Loneliness**

All of the participants shared a human need to be with someone, to be wanted by someone and to feel special to someone. Participants valued companionship and having someone to share experiences with was something participants looked for when



selecting a partner. This was important regardless of age or gender. The desire to alleviate loneliness appeared to be a facilitator to relationships for participants. Despite some participants claiming to be lonely, loneliness did not appear to be a barrier to forming a relationship but a possible driver to motivate them to form and retain relationships. As identified in the exploratory thematic analysis (see Chapter 4), the majority of participants had experienced some degree of rejection and abandonment which could have made the desire for companionship more pertinent. There appeared to be no clear connection between age, gender, ability to go out alone, number of friends, level of disability and the degree of loneliness felt. Peter, Caroline and Kerry appeared most isolated: they all had small social circles and limited or no contact with family.

Liam and Emma both identified their appreciation of other elements of the relationship beyond physical attraction. They enjoyed typical 'couples' activities' together such as meals out and the cinema.

*Liam: Do more things (when asked what he likes about being in a relationship)*

*Emma: Because I don't want to be on my own, the best thing about a boyfriend is you can go out and do things together*

Despite having a partner, Emma appeared fearful of being lonely and did not want to be alone.

*Emma: Well, the thing that makes me happy being with someone is I would rather live with someone, a partner, than being on my own because I don't like being on my own (when asked what makes a happy relationship)*

However, Emma and Liam had a good circle of friends, in contrast to some other participants, and both claimed to have best friends whom they saw regularly.

Similarly, Carrie and Joe valued the companionship their relationship provided. They, too, enjoyed having someone to share experiences with, such as going shopping in town and meals out. Joe said he would be lonely without Carrie but, unlike Emma, there did not appear to be a fear of loneliness but more an appreciation of their situation.

Few participants directly expressed their loneliness. Caroline expressed how she sometimes felt lonely and rejected by her family and desired this to be different. To

compensate, Caroline and John provided companionship and emotional closeness for each other as 'family'.

*Researcher: Is John like your family or not?*

*Caroline: Yeah, It does feel like that.*

*John: Yeah, it does*

The relationship between Caroline and John appeared built on companionship. Both went out unsupported, spent time visiting places together and sharing cups of tea. Both considered each other to be their best friend as well as partner. They enjoyed having someone to talk to and to share experiences with. It was touching that they were able to find this with each other following the abandonment and rejection they had experienced in their past.

*Caroline: That's the thing we both have lots of time for each other as we do a lot of talking and everything*

*John: Caroline's my friend, my best friend.*

Kerry was less explicit in describing her isolation. Kerry also had limited interaction with her family but did not say she was lonely. However, one could hypothesise that she may have used sex as a form of intimacy to alleviate her isolation, as beyond her sexual partners and staff she appeared to have little companionship in her life. Kerry valued Dean's company and friendship most of all. These attributes, caring; protective; reliable and friendly did not appear to represent 'passionate love' but more like 'protective and caring qualities'.

*Kerry: Um, yeah, we do yeah he keeps me company, friendly. Just talking to each other you know.*

Kerry and Dean were the only participants to live in their own flat (not in a staffed block). Although this was a positive step in Kerry's independence it appeared to make her more isolated socially compared to others who lived in communal settings. Kerry described a life that indicated that she was isolated and lonely and would have been more so without Dean's companionship. When asked about her social circle and friendships she was reluctant to provide any details or engage in discussion. Dean was also not present for the interview which explored people's social networks so it was not possible to comment on his situation.

*Researcher: Have you got friends there that you see [at day services]?*

*Kerry: Not many, few.*

*Researcher: Are there any that you get on with particularly well?*

*Kerry: No I just get on with them*

*Researcher: Do you have a best friend?*

*Kerry: No*

Alan did not attend the second interview where social networks were discussed so it was hard to determine if Alan had a large social circle. However, evidence from the first interview indicated that companionship and social interactions were important to him. 'Going out' was of major significance to Alan, suggesting that his wife's accident had a devastating effect on their relationship. He described how he 'missed' his wife even though she was still 'there', just unable to accompany him on trips out (without staff support). Her ability to do this appeared to be a higher prized function than her personality or physical attributes. The accident took away their time alone together and he was now unable to care for his own wife by pushing her wheelchair, which may have possibly been demoralising for him as a husband and a man.

*Alan: It feels different now she has the, you know, hip.*

*Alan: Well you miss them don't you? (when asked how her being unable to go out unsupported affected the marriage)*

Peter did not appear to be perturbed by his perceived isolation and rejected staff encouragement to widen his social circle: it appeared that his wife provided all the interaction he required. From his description, Peter also had a small social circle and, beyond his housemates, he had no other friends. During the course of the interviews Peter and his wife separated (at her request). At the time, Peter appeared unable to entertain the possibility that this could be permanent and possibly devastating for him as it would mean not just the loss of a partner but his whole social world.

Like other participants, Mary clearly enjoyed the companionship her partner provided and she liked the shared activities they engaged in. The couple also had some shared interests such as dancing and going to the local pub.

*Researcher: What's good about having a boyfriend?*

*Mary: Sometimes I go and spend the night out or have lunch or something. Yeah cinema as well*

Despite enjoying the companionship, Mary said she had a busy social life and did not feel lonely. Mary stated that she attended various social clubs and was friends with the people who lived within her staffed block. Mary was also the only person to state how

she enjoyed time alone. Mary received more support than other participants and staff supported her in attending a range of structured activities. This possibly ensured she was adequately stimulated and not lonely.

### **Supportive Relationship**

Relationships were portrayed as not just alleviating loneliness but also providing support to each other either practically or emotionally. Carrie and Joe provided emotional support to each other and supported each other through difficult situations.

*Researcher: Did you report it to the police? [attempted rape]*

*Carrie: Yep I did.*

*Joe: I was in there to hold her hand.*

*Researcher: That's awful. Did you get any counselling or anything?*

*Carrie: No*

*Joe: I was there*

*Carrie: Joe did it [counselling for her].*

*Carrie: [to Joe] Thank you for being my rock*

Peter appeared to enjoy 'taking care' of his wife by completing household tasks such as cooking and other more intimate tasks for his wife such as washing her back. He also appeared to enjoy it when she reciprocated and did tasks for him. It was unclear if they provided each other with emotional support, but it was evident at some point prior to their separation that there had been a level of reciprocity. Liam and Emma also supported each other. Like Peter and his wife, this support replaced the possible need for staff support. Liam discussed how Emma cared about his welfare and 'looked after him' by providing emotional and practical support. Kerry also felt Dean 'looked after' her and she indicated that his support could be practical as well as emotional.

*Liam: Yeah she [Emma] cares about me and about me getting ill. Don't want to get I'll get headache. Yeah keep me well look after me.*

*Emma: We look after each other don't we.*

*Kerry: Oh he looks after me he knows, Because he looks after me and because I have eye problems at the moment he looks after me when we go to mum's he looks after me when I am on the train and stuff.*

In summary, loneliness can be a facilitator of a relationship, and participants enjoyed having a special someone to engage in activities with, to share experiences and to receive support from in differing capacities. Participants appeared motivated to meet

their 'love and belonging needs' or, as defined by attachment theory, to make a secure attachment to another person (Bowlby, 1979). There was a fear of loneliness which was not influenced by the number of people participants came into daily contact with as their living situations typically included numerous staff and housemates. This suggested the significance of their relationship with their partner, providing more than just a 'presence'. It was a special exclusive relationship with a reciprocal partner to fulfil their 'love and belonging needs'. The more isolated the person was, the more significant their relationship became. In some cases a partner constituted their main social outlet to the world or a substitute family. Participants with a limited number of friends were possibly fearful of expanding their social circle due to perceived threats to their 'safety and security needs' based on their past abusive experiences. Having a partner also enabled participants to engage in valued social conventions which were typical of adults without a learning disability, such as having 'dates'. Without a partner they would have been excluded from these, therefore being in a relationship, and being seen to engage in these activities, could be viewed as a way to demonstrate that they are no different from the wider society and possibly increasing their ability to meet their 'self-esteem needs'. Participants desired a supportive partner. Having someone who cared and supported them was possibly reparative for participants who were abandoned or rejected by their family. As indicated by attachment theory, participants demonstrated a desire to be wanted and to be special to someone.

## **5.2 Theme Two: Sexual and Physical Relationships**

The second theme identified from the participants and their stories was sexual and physical relationships. The two sub-themes which appeared to be significant in participants' sexual and physical relationships were:

- Engagement in sexual acts

- Lack of children/ fear of pregnancy

### **5.2.1 Sub-theme One: Engagement in Sexual Acts**

#### **Fulfilling physical relationships**

Enjoying a physical relationship (penetrative sex or not) appeared to be a facilitator in relationships and was valued by participants. Only Liam and Emma, and Dean and Kerry (two couples) out of the eleven people interviewed claimed to engage in a sexual relationship (penetrative sexual intercourse). None of the other couples discussed or made reference to any other form of sexual foreplay involving stimulation of the sexual

organs. The remaining participants (excluding Alan) expressed their enjoyment of a physical relationship but their relationships appeared to focus on less sexual acts such as kissing, cuddling or holding hands. This conformed to the commonly-held belief that people with learning disabilities were 'innocents' and devoid of passionate sexual desires (see Section 2.4.1).

Liam and Emma were the most open in expressing their desire for a sexual relationship and the satisfaction it brought them as a couple. It was clear that he and Emma enjoyed a loving sexual relationship. Emma expressed how sex was not just physical and that she felt sex was an instrument for developing intimacy.

*Emma: I wanted to get closer to Liam [through sexual intercourse].*

*Liam: Share everything with each other, sleep with each other*

Carrie and Joe did not engage in a penetrative sexual relationship despite being sexually attracted to each other and employing sexualised terminology to describe how they felt about each other. They had unsuccessfully attempted to engage in intercourse. Carrie suggested the issue was physiological. There was an attempt to explore these issues further, but the couple found it too uncomfortable to speak about therefore it was not pursued.

*Researcher: You said last time that you didn't have sex do you?*

*Carrie: No, I find it difficult.*

*Researcher: What painful?*

*Carrie: No not painful, connecting.*

*Carrie: Hard to push*

It was disappointing that this young couple were unable to enjoy this aspect of a loving relationship and it was unclear what support they had received to overcome what appeared to be physiological issues. Carrie and Joe enjoyed other aspects of their physical relationship such as kissing and, hugging. They were physically affectionate in the interview and saw physical affection as a demonstration of love for a partner

*Researcher: So how do you know when someone loves you?*

*Carrie: Cuddles*

*Joe: Or kiss*

A barrier to a fulfilling physical relationship appeared to be having differing preferences for the level of physical contact within the relationship. Caroline and John have been

together for over ten years but do not engage in a penetrative sexual relationship. Caroline suggested she would have liked a more sexual relationship but claimed John was reluctant. Caroline said John's desire to engage in a physical relationship had significantly decreased since the start of relationship, which was a disappointment to Caroline.

*Caroline: We used to do a lot of cuddling and kissing in the younger days didn't we but he it just seems like it is worn off him*

When asked why the relationship lacked a physical element Caroline explained it was because John became embarrassed and John agreed.

*Caroline: He gets really embarrassed because he doesn't like holding my hand or hugging or cuddling me in public he even if he knows someone he doesn't he just gets embarrassed don't you. Even when we are on our own he is still must feel embarrassed in his mind because he still doesn't want to do what he did*

John felt uncomfortable discussing this topic and it was not really explored in depth. It was possible that John's lack of desire may have been physical. He had experienced health issues in recent years and it was unclear if this or his medication had any effect on his sex drive. It seemed that the couple never had any support or counselling around the lack of physical contact within their relationship. It was also unclear what implication this lack of passion had for Caroline, who had suffered many rejections in her life, and the impact this could have had on her self-esteem. However, despite John's lack of enthusiasm for a physical relationship, they do cuddle and kiss. Perhaps it was not as often as Caroline would have liked and does not have the desired level of passion, but John does engage in this and views it as a way to physically express his love for Caroline.

*John: Give her a cuddle, a hug and tell her I love you*

Staff privately informed me when I visited the house that Peter did not have penetrative sex with his wife, although I had not requested this information. Peter's level of physical affection appeared less sexual than with the other couples interviewed and focused on more 'innocent' acts such as hand-holding and cuddling.

*Researcher: What do you like about holding hands?*

*Peter: It is actually nice to hold hands.*

This couple separated during the course of the interviews. This was difficult for Peter to understand, especially the imposed lack of physical contact. Staff had explained to him that this was his wife's choice and he must respect it but he found this difficult, suggesting that physical affection was an important aspect of the relationship to him. Like Caroline, Peter had also suffered many rejections in his life and it is clear that this rejection was also difficult for him.

*Peter: I think she [staff] said we don't want to be close, close together. That's what she [staff] said.*

*Researcher: What being just friends?*

*Peter: I like it when we stay as a couple.*

### **Sexual Abuse by a Partner**

Both couples who engaged in penetrative sexual relationships (Liam and Emma, and Kerry and Dean) included a female partner who said they had previously suffered sexual abuse. The only women in the research who had engaged in penetrative sexual relationships had previously been sexually abused. No clear reason for this presented itself. Three of the five women had experienced sexual abuse or attempted sexual abuse from an ex-partner or family member. This did not appear to have been a barrier to enjoying a sexual/physical relationship. It appeared that loving relationships with a considerate partner went some way to minimising the impact of that abuse and enabled these women to enjoy intimate relations.

Emma suffered a sexual assault by an ex-partner, and claimed the effects of this led to a period of poor mental health and hospitalisation. Despite this, Emma was able to overcome her fears, trust Liam and engage in a sexual relationship. She described how this was possible due to Liam's sensitivity and patience. Their decision to engage in a sexual relationship was reached together.

*Emma: He [Liam] doesn't force me like the other ones used to. He [Liam] is nothing like my other two boyfriends.*

Kerry was sexually abused when she was younger, which may have had an effect on her ability to view sex as an enjoyable, intimate act. Although her lack of enjoyment was not stated explicitly, there was little enthusiasm or warmth in her voice when discussing sex. Kerry made no other reference to their physical relationship beyond their having sex, which, based on her tone, did not seem to be an important aspect of the relationship to Kerry. Her lack of enthusiasm to discuss their sexual relationship did



not seem to be the result of shyness or embarrassment, as Kerry was able to discuss other personal topics with ease, such as Dean's sexually transmitted diseases. Both Kerry and Dean appeared to have had numerous sexual partners.

*Kerry: I've had loads of boyfriends but um too many to go into*

Kerry had felt pressure to have sex from previous partners and this had caused friction and the termination of the relationships. This suggested that Dean differed from her previous partners, although this was not explicitly discussed.

*Kerry: I didn't want to do anything you know like relationship have sex with him [ex-partner] he didn't like it and got all huffy gruffy and all this I said to him 'excuse me when I don't want to do it you don't force me to do it' and he was forcing me and forcing me to do it. So I told him get your clothes on, get your shoes on and get out of the house. I don't want nothing more to do with you it is over. I told him it was over because I couldn't cope.*

### **External 'Barriers' to physical relationships**

Mary, in her interview, suggested other 'external barriers' to her physical relationship. In the case of Mary it was unclear who this 'external' force was. Mary and Gary did not have a penetrative sexual relationship and Mary appeared appalled at this suggestion. Mary felt that it was not appropriate for another person to see her naked, despite numerous staff supporting her with intimate personal care. Mary used emotive language when discussing her choice to not be naked in front of Gary.

*Mary: 'Got to leave it [nightdress] on'*

It was not clear who instigated the 'got' in this sentence. When asked who said that, Mary just repeated it and it was unclear who instructed her of this or if it was just how she felt. However, the way it was said it felt like it was an instruction she was following rather than a self-imposed restriction. Nonetheless, she enjoyed showing less 'private' parts of her body [her legs] to Gary, despite her disapproving feelings towards displaying nudity.

*Mary: He [Gary] like touching my leg sometimes.*

*Researcher: Gary like touching your leg sometimes?*

*Mary: Yeah, I wear my shorts I do.*

*Researcher: So you show Gary your legs?*

*Mary: Yes.*

Mary was the only participant from an ethnic minority with a tradition of holding more conservative values and it would therefore be likely that she would hold more traditional attitudes regarding sex (see Section 2.2). Perhaps Mary believed it was more acceptable to enjoy these less sexualised, but still sensual, elements of her body. This was also compounded by Mary's comments regarding kissing and cuddling, which suggested that she was reassuring or convincing herself that kissing and cuddling were accepted expressions of physical love as opposed to anything involving genitalia. The term 'It is alright, isn't it?' was used three times by Mary. It was thought that this phrase suggested that she was seeking approval from either myself or the staff (who were present in this interview).

*Researcher: What do you like about it, why do you like cuddling?*

*Mary: It is alright isn't it?*

*Researcher: Ok what about kissing does kissing feel nice?*

*Mary: It is alright isn't it?*

In summary, with the exception of Alan who was not asked, all of the couples enjoyed a physical relationship of some description. All of the participants were able to describe physical elements of their relationships that they found pleasurable and it is probable that their enjoyment played a role in bringing and keeping the couples together. The participants also desired a partner who was able to show them physical affection. Participants who had been abused were able to use this experience to identify what they did not want in a partner, such as someone who pressured them or was abusive in any way. Most of the participants engaged in what could be defined as 'innocent' sexual acts such as kissing. The sexual behaviour of most couples did not correlate with Maslow's theory that sex was a 'basic need', as some couples were engaging in loving relationships which were devoid of sexual intercourse. It is possible that to some individuals these acts (kissing etc.) were daring and highly sexual, especially when considering the control they have experienced regarding sexual expression both within their own lives and historically (as described in Section 2.2 and 2.4.1). Maslow recognised affection as part of his 'love and belonging needs' which are 'higher psychological needs' however, based on the participants' descriptions, affection appeared more important than sex which Maslow classified as a 'basic need'. Affection is central to attachment theory, required by infants from caregivers to assist in forming loving attachments (Ainsworth and Wittig, 1969). Some participants explicitly stated that they saw physical affection as a way of demonstrating that you loved someone or were special to someone. For some participants, displays of physical affection may have been a way of feeling secure about their partner's feelings towards them,

reassuring them physically that they were wanted. The exclusivity of a physical relationship could be valued as a way of demonstrating that their relationship was 'special' compared to others. Participants desired a partner who showed physical affection and engaging in a positive physical relationship of some description was a facilitator of the relationship and contributed to keeping couples together.

### **5.2.2 Sub-theme Two: Lack of Desire/Expectation for Children**

A sub-theme of sexual relationships was the theme of children: no couple had children with the exception of Dean who had four daughters from a previous partner. Dean appeared unenthusiastic and unforthcoming in relation to his role as a father. Kerry had never met his daughters, had no involvement in their lives and did not appear to have any desire to. Dean had little contact with them.

*Dean: I spend more time with Kerry than with my kids you know.*

There was a hint of jealousy in Kerry's conversation regarding Dean's children as she continually repeated that Dean did not see his daughters and her tone of voice suggested she was happy with this arrangement. It is possible that she felt excluded from this portion of his life and her inability to share his role as parent. Dean's children are cared for by his sister. Dean expressed a desire to have children with Kerry, who suggested that she felt a pressure to have children and she was the only woman from the interviewees who appeared pressured to conform to social norms and procreate.

*Kerry: We will have children when we feel it. If I don't want a baby of my own I can. Sometimes people don't have to have children do they? People just don't want a child*

All female participants (and Liam) expressed negative feelings regarding parenthood. The general feeling expressed among participants was an inability to cope with parenthood for a diverse range of reasons. Kerry felt she would be unable to cope with motherhood and linked this to her physical disabilities which appeared to be a minor condition, rather than her learning disability. Kerry appeared not to like being defined as a person with a learning disability and therefore it would be surprising if she had linked her inability to cope with motherhood to this. It was suggested by staff when arranging interviews that Kerry's mother had learning disabilities and it was possible she may have internalised her mother's own failings and feared she would replicate this if she had children.

Unlike Kerry, Caroline was adamant that she did not want children (this would not be a realistic possibility due to her age). She claimed her lack of children was due to a self-perceived weakness in her personal attributes, a lack of patience. This was not specific to her learning disability but related to her personality.

*Caroline: I wouldn't want kids, no I don't have enough patience with them. I like seeing them with other people but I wouldn't have enough patience if it was mine so, no, I wouldn't want kids.*

How Caroline presented in interview suggested she lacked qualities associated with 'self-esteem needs' such as confidence and little has been expected of her throughout her life from her mother and teachers. If she had been supported better when younger she may have had more confidence in her abilities and been better equipped to ascend Maslow's hierarchy. It was possible that these were parroted statements she had heard in childhood regarding her or her mother's ability to be a mother. Caroline implied she had a poor relationship with her mother and was possibly fearful that she, too, would have a poor relationship with any potential children.

*Caroline: They [parents and teachers] decided that I should stay on at school for work experience because I couldn't, I wasn't, I couldn't cope with a job or anything*

Liam and Emma both said they did not feel ready to have children; Liam (unlike Kerry and Caroline) linked his lack of desire for children to his learning disability, feeling he would be unable to cope. There was also some suggestion that he felt he would be a bad father due to not knowing how to respond in an emergency. Emma also confirmed that she shared his fears.

*Liam: I don't want a baby I don't, too difficult for us. Like a baby needs someone with it to take it to hospital. Me and Emma don't know what to do with it.*

Liam's fears appeared to be focused on the practicalities of caring for a small infant rather than considering the wider picture of having a family.

*Liam: Babies are difficult to look after, Babies aren't easy: change it, feed it.*

Despite Emma's fears, she had not completely ruled out the option of parenthood, as she said 'not at the moment' when asked if she would like a child. However, at the time of the interview, Emma appeared fearful of an unplanned pregnancy. Despite receiving the Depo-Provera injection and using condoms, she still feared it could happen. The 'doubling up' of contraception suggested an excessive fear of pregnancy. It was unclear

if this 'double contraception' was instigated by Emma or external parties such as staff, doctors or family. It would be unlikely that people without learning disabilities would typically employ a double use of contraception with a long-term partner. Carrie and Joe were not engaging in sexual intercourse, yet Carrie had an implant fitted. This implied there was a fear of unplanned pregnancy. However, it was unclear if this fear was Carrie's or other external parties.

Carrie, like Liam, considered it too difficult for her to have a child and appeared unlikely to change her position. Carrie attributed this to her having a learning disability rather than just general lack of knowledge around caring for small children. Like Caroline, it was unclear if these were her views or statements she has internalised from staff, family, friends or professionals.

*Researcher: What do you think having a baby would be like?*

*Carrie: Being special needs and Down's syndrome we couldn't cope with a baby.*

Carrie felt that it was because she and her partner had Down's syndrome that they would be unsuitable parents. Carrie's views went beyond her as an individual and incorporated all people with 'special needs' (her words) as a whole, referencing a documentary she had seen on the topic as an example

*Researcher: There was another one about people having a baby, what do you think about that?*

*Carrie: Oh I agree with getting married but not having the baby.*

*Researcher: What, any person with special needs?*

*Carrie: Yeah.*

Joe stated that he did not feel ready for a child, which was unsurprising as he was in his mid-twenties. He did not comment on Carrie's view that people with learning disabilities should not have children.

Mary was the only female who was not asked if she would have liked a family. Mary should have been given the opportunity to answer this question, however, it never felt appropriate to enquire as she was very opposed to the idea of engaging in a sexual relationship. Without even being open to this possibility it would be impossible to ask her to consider the possibility of her becoming pregnant.

All of the older males (Peter, John and Alan) said they would have liked to have children. This would not have been physically possible due to their partner's age, however this was not acknowledged by them, neither was the fact that they were not

engaging in sexual relationships. Liam (who had sex) and Joe (who tried to have sex) were the men who did not want children. The older men made no further comments on this subject, suggesting this was not something they had thought extensively about. This suggested it was not something they had ever expected or had even consciously occurred to them.

Excluding Dean, no participant had children. Maslow (1943) considered the role of a parent as 'socially valued' and such roles assisted people to fulfil their 'self-esteem needs'. No female or younger male participants wanted children at this time and all stated their reason for this was their inability to cope with raising a family. They all felt they would not be able to cope with parenthood either due to their personality, physical or learning disability. Based on the participants' comments, it could be argued that people with learning disabilities do not share the stereotypical life goals of many people without learning disabilities, which is to have their own family with a partner. To imply that all people without learning disabilities desire children would be a vast generalisation, people remain childless for various reasons such as lifestyle choices, focussing on a career, lack of partner/suitable partner, insufficient resources or biological difficulties. What appeared significant for the participants was they all rejected parenthood due of a perceived weakness which was either physical (Kerry), emotional (Caroline) or directly due to having a learning disability (Carrie). This appeared due to a lack of confidence in their abilities as potential parents, which resulted in a lack of expectation for parenthood. It is possible that this lack of confidence is apparent in individuals without a learning disability. However, such individuals see their peers succeeding as a parent, which may inspire confidence in their ability to cope in this role. Sadly there are few 'success stories' for people with learning disabilities to inspire couples. This, combined with a fear from staff regarding their ability to cope, does not inspire confidence in potential parents with learning disabilities. An alternative interpretation could be that participants were displaying a high level of insight into their own capabilities, acknowledging that they required support to live independently and were realistic regarding their capabilities as parents. Participants may have been aware of children being removed from parents with learning disabilities into care, either through the press or knowing a parent personally, and not wanting to experience this distress.

In this instance, a shared desire to not have children could have been a facilitator in relationships where both people shared the same perspective. It was unlikely that the desire/lack of desire to have children influenced partner selection as parenthood did not appear to be a life choice participants wanted, expected, or in some cases, even

considered.

### **5.3 Theme Three: Influence of Staff/Group Living**

The third theme was the influence of staff and group living on the following sub-themes:

Accommodation

Restrictions from staff and housemates

Support from staff

#### **5.3.1 Sub-Theme One: Accommodation**

A sub-theme of influence of staff/group living was accommodation. With the exception of Dean and Kerry, all of the participants lived in a 24-hour staffed environment. Peter and his wife and Mary lived in small flats/bedsits in a converted house with 24-hour support. All of the others lived in supported living services or care homes which were staffed 24 hours a day. The findings suggested that the accommodation participants lived in, or the choices they made/had available regarding their accommodation, influenced their relationships.

#### **Lack of stereotypical expectation regarding living situation**

Some of the participants expressed a desire to live alone as a couple in the future, but others had not considered or, did not want this. This could be suggested as atypical in mainstream society (Duncan and Phillips, 2010). However, it could be argued that people with learning disabilities often sit outside of mainstream society and, as a result, may hold different values and expectations based on their experiences. It was mainly the older couples from the participants who were content living in a group environment, either as a couple or alone. Almost all of the younger participants were keen to live alone with a partner and their aspirations reflected societal norms.

*Liam: Yeah, one day, yes, get a house together (he and Emma)*

*Researcher: What would you like in the future for you and Carrie?*

*Joe: Own place with no babies.*

*Researcher: We were talking about the future. What would you like for you and Joe?*

*Carrie: I want to move out one day in the future.*

It was unclear why older participants had not considered the option of living alone as a couple. Alan did not appear to have considered that he and his wife may have wanted to live together, rather than with others, as other married couples typically do.

*Researcher: Did anyone suggest living alone, living just the two of you?*

*Alan: No*

*Researcher: So you were always going to stay where you are?*

*Alan: Yeah*

Mary also appeared confused when asked if she would ever like to live with Gary, suggesting that she, like Alan, had not considered this and had no expectation to live alone with Gary. Mary and Alan appeared to have higher support needs than other participants (with the exception of Peter, who had already lived alone with his wife in a flat in a 24-hour staffed block prior to their separation). The embodied reality of their learning disability and associated higher support needs may have impacted on the housing options available, possibly making it too costly for Alan or Mary to move into their own home with a partner and receive 24-hour support (Mary's bedsit would have been too small for two people). The younger couples had lower support needs and therefore more possibilities for living alone with a smaller support package.

Caroline and John appeared to have lower support needs and had lived together in a self-contained flat within their current care home but were now living in separate rooms within the same location. The reasons for the unsuccessful attempt to cohabit were unclear apart from John wanting more space. This might relate to the fact that he had spent almost his whole life in institutions. The couple appeared happy with the current situation and expressed no desire to live together. It was unclear if the possibility of a flat (possibly with two bedrooms) had ever been discussed as an option.

*Caroline: He seems to be happier and I am alright now because I like it like it is because I can spread my things when I want to. If I want to make I can make a mess of everything so it's nice and he still comes and uses our bathroom in the morning which is nice.*

Participants may have had less expectation of living alone based on their own past experiences. As discussed in the exploratory thematic analysis (in Chapter 4) older couples were more likely to have experiences of institutional care, suffered more rejection and be more isolated. This would possibly make it more appealing and acceptable to remain living in their current environment. All of the older participants liked where they lived and had no desire to move. It was possible that this was a place where they felt wanted and secure. Their relationships appeared no less significant or committed for the lack of desire to live alone together.

Kerry and Dean were the only couple who had enough space to live together but actively chose to live apart. This was due to the financial implications of moving in



together, as they each had their own flat but were afraid that they would lose their benefits if they moved in together. In this case, the benefit system did not encourage the co-habitation of people in receipt of benefits. Maslow's historical view of marriage was believed to increase financial security, however for people with learning disabilities in receipt of benefits, marriage can lead to a decrease in financial security. Maslow's theory could be further interpreted to suggest that benefits supplied to people with learning disabilities ensures their 'basic needs' are met (shelter/food), however higher levels of the hierarchy such as autonomy to choose to live with a partner (self-esteem needs) are compromised as a result. The situation is similar for people without learning disabilities in receipt of benefits, but their prospects for securing employment are more optimistic, affording them more choice within this situation. Couples who have a learning disability, such as Kerry and Dean, are more likely to rely on benefits to supplement their income and have poorer employment prospects.

*Kerry: if you are on benefits basically they will take it away from you. I don't know the story but all I know is that if we got married then we couldn't live together we would still be in separate houses*

*Dean: If we got married we would lose our money and that's what I don't want to do, lose my money*

Younger participants had less experience of institutional care and all (excluding Kerry) grew up within a family environment and all (excluding Kerry) wanted to live with a partner in their own flat with less staff support. Liam and Emma expressed unhappiness in their current location claiming they were restricted by staff and were unhappy with the behaviour of a housemate. However, they continued to live at the property. It was unclear why they had not begun the process of moving. It was highly probable that this was also a practical issue. Living in supported living accommodation, with a social care contract for support and in receipt of housing benefit, makes it more complicated to move accommodation compared to a member of the general population. Moving home typically involves the agreement of the care manager and is often a slow process. This demonstrates how people with learning disabilities experience additional barriers to relationships compared to the people without a learning disability. It could be hypothesised that this could have contributed to the delay for the couples who wished to move into their own home, a possible potential mental barrier to start the process.

In summary, the expectations participants had regarding their living situations did not act as either a barrier or a facilitator to relationships (especially with so many

relationships starting in shared accommodation), however, my research reveals a difference between younger and older participants. Younger couples wanted to live alone with a partner but currently felt unable to do so because of external factors. Older partners who were living apart expressed no desire to change this. Living in a property alone with a partner did not seem to have been suggested or explored by staff. However, this may not have been an option due to the embodied reality of some individuals' learning disability, such as their ability to undertake day to day tasks and manage risk and safety. There were challenges when moving from a group home to a home just with a partner in terms of funding for support, benefit payments and additional restrictions/delays such as agreements from social workers. This emphasised the external barriers which existed for participants in relation to ascending Maslow's hierarchy. This was coupled with the emotional challenges of leaving an environment where individuals felt secure and supported. Their current accommodation was meeting their 'safety and security needs', which may have decreased their desire to move. Participants, who had experienced issues such as those discussed in Chapter 4, may have highly valued a home where they felt safe and secure. The findings suggested that adults with learning disabilities have different expectations of their living situations based on their own personal experiences and expectations. Those who grew up in care homes or institutions appeared content to remain in a group environment, while those who grew up within the family unit aspired to live alone with a partner and had expectations that were similar to the majority of adults without learning disabilities.

### **5.3.2 Sub-theme Two: Restrictions placed on relationships by Housemates and Staff**

#### **Restrictions from housemates**

Some participants said that living in a group environment created barriers to their relationships. Joe, Liam and Emma were the only participants to explicitly state that their current living situation impacted negatively on their relationships, which they claimed was due to jealousy from housemates. Joe claimed his relationship was affected by a housemate who was jealous of his relationship with her best friend Carrie: this resulted in friction within both the relationship with the housemate and with his wife. The main issue highlighted by Joe was the lack of space and privacy from this individual he and Carrie had as a couple.

*Joe: She is too much [housemate].*

*Researcher: Is she, what do you mean?*

*Joe: She wants to spend time with Carrie all the time and not me.*

*Researcher: Does that cause problems?*

*Joe: Yep.*

Joe and Carrie claimed this housemate intruded on their privacy by trying to enter their room when they were attempting to have sexual intercourse.

*Researcher: You tried [to have sex]?*

*Carrie: Pamela tried to come in*

*Researcher: That's a bit difficult then. Do you not have a lock?*

*Joe: Yeah we did, we tried that*

*Researcher: Yeah what happened?*

*Joe: She keeps knocking*

*Carrie: We gave up on that didn't we?*

Carrie, who claimed to not see the housemate's behaviour as a problem, further complicated Joe's concerns. Carrie suggested in interviews that she enjoyed the attention she received from both Joe and her friend. It was unclear if staff were aware of this person's behaviour and, if so, what action had been taken to address it.

Liam and Emma claimed they lived with a housemate who was jealous of their relationship and wanted a boyfriend for herself. They said it had a negative effect on their relationship. They claimed this person's jealousy resulted in a ban on the display of physical affection in the communal areas and being relegated to their own bedrooms if they wished to show any physical affection towards each other. This identified an area of tension for staff, who appeared in a difficult situation of deciding whether to allow Liam and Emma to express their love freely or ensuring that others who lived there felt comfortable and were not upset by their public displays of affection. This emphasised some of the issues involved with people's relationships within communal living, and Emma and Liam expressed a clear desire to live alone as a couple even though they had to remain living with others. It was unclear when they planned to move or what restricted them, but it was apparent that their current living situation was not their preference. The staff had a challenging task of balancing the rights of the couple with the rights of individuals within their accommodation. Emma and Liam perceived the restrictions as impacting on their 'love and belonging needs', although staff may not have seen it this way because the couple could engage in whatever physical contact they desired in private.

*Emma: I think it is really hard because if she wanted a boyfriend she could go and find one.*

*Why should we stop cuddling because she doesn't like it.*

*Both: We are not allowed to [cuddle] downstairs.*

*Emma: We just wanna cuddle and we can't.*

No other participants suggested any negativity towards their housemates. This was unsurprising when considering the findings in 5.1.3 (Companionship) regarding how many people with learning disabilities were lonely, that housemates often formed part of their social circle and homes were often the places where relationships began. The participants who experienced issues with housemates were those who were younger and living in communal settings: based on their accounts, the issues regarding relationships appeared to be rooted in jealousy, such as the desire to have a partner of their own. Participants were able to overcome issues with housemates relating to their relationship but this could have possibly been off-putting for less secure or committed couples.

### **Restrictions from Staff**

Only Liam and Emma directly stated how they felt staff created barriers to their relationship. Emma and Liam were keen to move into their own flat where fewer restrictions would be imposed. It appeared as if Liam and Emma were going through a 'second adolescence', having left home as adults but facing restrictions that were more typical of teenagers living in a family home. Examples of restrictions from staff included being unable to share a bed on weekdays and being unable to show physical affection at home to each other in communal areas of their home.

*Emma: We only do at weekends [share a room]*

*Liam: Or half term...We can do what we want in our own house without being told what we can and can't do.*

It was unclear why the restriction around sleeping arrangements had been put in place. Controlling their movements could be considered unlawful under the Mental Capacity Act 2005. There was no evidence to suggest that the couple had challenged staff, instead appeared to passively accept the restrictions with a degree of resentment. As previously stated, staff experienced conflict in respecting the rights of the couple over those of the individual and possibly perceived the restriction as a compromise. However, some restrictions appeared unjustified and possibly implied control by staff as opposed to support. For instance, although adults, it appeared that some participants still felt they required staff's permission to engage in normal adult activities such as sexual relationships/sharing a bed together. No other participants reported any restrictions from staff and they often reported how supportive staff were regarding their physical relationship. Despite the perceived lack of restrictions there still appeared to

be an element of control (or perceived control).

*Carrie: I asked the support staff if Joe can move into my room and they said that's fine. I spoke to Joe and said about coming into my room just for one night and seeing how it felt if he liked it or not. Then we tried it and he liked it. Didn't you?*

*Emma: I went to the staff to see if I could actually sleep with him and they said [starts laughing] to see if it is alright [sleeping together] because of where we are living in a house with other people.*

Mary did not explicitly state any restrictions staff enforced on her. However, Gary had never stayed the night with Mary, although this did not seem part of Mary's expectations and unlikely she would have ever asked for this as she appeared surprised when this suggestion was raised. Based on observations between staff and Mary, it seems unlikely that staff would have encouraged or permitted this. Due to the embodied reality of her learning disability it was unclear whether Mary would have the capacity at this time to engage in sexual acts; possible evidence for this was that she was unaware what condoms were when asked. It was possible that she may have been able to have a sexual relationship with sex education support.

*Researcher: Does he sleep over here, sleep the night?*

*Mary: My boyfriend he goes to his own flat*

Kerry, when living at a care home prior to moving to her own flat, also showed no expectation that her partner should be allowed to stay with her in her own bed.

*Researcher: So you used to have to ask if you could bring someone into your to come into your house?*

*Kerry: Because it weren't just my house was it? Some other people's house*

*Researcher: Yeah. Could people stay over overnight if you asked?*

*Kerry: No there would not be enough room*

This restriction may have been due to the type of accommodation Kerry lived in rather than anything imposed by staff. The property was a registered care home, and an on-line search demonstrated that many such establishments offer the opportunity for overnight guests. This suggested that the restriction was not due to regulation but was enforced by staff to protect residents. It was possible this restriction was in place, not just to protect Kerry but also other more vulnerable residents. If staff knew little about her partner at the time, or they considered him a potential risk, staff had a duty of care

to manage visitors safely and to uphold residents' 'safety and security needs'.

It was difficult to interpret the staff's actions as merely punitive: from participants' discussions the impression was that the staff were protective towards the people they supported and appeared not to want them to suffer abuse or heartache. This was conveyed in a conversation between staff and Liam where staff wanted assurance for his feelings towards Emma. This appeared to be beyond what was required of a support worker.

*Liam: Staff asked me and said 'are you sure about this and you won't hurt Emma? And I said 'Emma knows me and I love her' and we had a really good chat. She said 'do you want someone else' and I said 'no I don't want someone else I want Emma and that's it'.*

In summary, some participants had experienced restrictions from staff regarding their relationships at some point in their lives and this appeared to be centred on behaviour with partners within a communal home. Some participants perceived restrictions surrounding sexual behaviour and did not see a sexual relationship or sharing a bed as an automatic entitlement as an adult. Overall, staff were not considered punitive and it appeared they believed they were ensuring the best outcome for participants. However, there were examples of staff behaving in a controlling manner, such as not making it possible for residents to share a bed on weekdays. Staff were in conflicting roles and observations suggested that they were encouraging people to be autonomous which may have assisted in developing their self-esteem, while also having a duty of care to keep them safe and meet their 'safety and security needs' by following the regulations and expectations as directed by their organisation or the law, regardless of their own personal views. It was possible that less committed couples could have been disheartened by the restrictions imposed by the staff and the negative influence of housemates and terminated their relationship as a result. However, those who remained together could feel more connected as a couple. Most couples demonstrated that, despite threats to their 'love and belonging needs', they remained secure in their attachments to each other. The exception was Peter, who was secure in his attachment to his wife, but there was little evidence of his wife continuing to feel attachment towards him at the time of the interviews. The separation, enforced by staff, impacted on Peter's ability, to continue meeting his 'love and belonging needs' through their relationship.

### 5.3.3 Sub-theme Three - Staff Support

As discussed in the previous Section the interviews revealed that staff often found themselves in conflicting roles. They were expected to both encourage autonomy and independence and to protect the people they had some responsibility for under their duty of care as support workers. Staff appeared in a dual role, at times reflecting the role of friend and confidante and at others a more authoritarian/protective role.

#### Protection from abuse

The staff's protective feelings were perhaps to be expected considering some of the participants' abusive relationships (see Chapter 4). The level of support required was dependent on the situation: staff either fulfilled the role of protector ensuring their 'safety and belonging needs' were met by confronting abusers or the facilitator of their 'self-esteem needs' by providing an advisory role supporting participants in addressing issues, therefore increasing their autonomy and self-confidence.

*Emma: I told the staff and they phoned up and they told the staff [when a partner was abusive] and they made him give the money back to me*

Emma's staff had the legal, and arguably moral, responsibility to protect the people they were supporting. However, this responsibility was not acknowledged by all staff. John had experienced physical abuse from a female partner living in the same property, but claimed he had no support from the staff team at the time (a different provider to his current one), despite him making them aware of the abuse. It was unclear whether, if the roles had been reversed and it was a male physically abusing a female, the staff's actions would have been different.

*John: She pulled my hair and took my CDs*

*Caroline: You complained about the staff not being particularly nice didn't you where you were?*

The way in which John was assaulted by his ex-partner pulling his hair and stealing his possessions may have been interpreted by staff as infantile and more representative of sibling behaviour rather than what is typically defined as domestic violence. Viewing it in this way could have made staff less likely to intervene or view the behaviour as abusive. If staff adopted this perspective it could indicate an element of infantilising people with learning disabilities and possibly abusive, given staff failure to uphold their duty of care to safeguard John from abuse.

Peter was protected by staff from abuse from his wife's family (discussed in Chapter 4).

However, they also appeared to try and protect him from the reality that his marriage may be over by claiming it was just a 'bad patch'. It was clear that staff were trying to reduce his suffering but this could be seen as infantilising Peter by not acknowledging the gravity of the situation. Peter appeared to value the interview that took place with me after his separation as he was able to discuss his situation and sadness with an independent person who did not attempt to pacify him.

### **Developing Autonomy**

Staff fulfilled an advisory role for all of the participants. The type of advisory role appeared to range from factual advice to more informal emotional advice. By giving advice staff were providing participants with the guidance and information to make their own choices thereby increasing their autonomy and assisting in the fulfilment of their 'self-esteem needs'.

Although Mary was unaware of the function of condoms, staff seemed able to provide frank and open advice regarding sexual relationships, especially regarding contraception. Staff appeared open and direct when providing advice around personal safety, empowering choices and eliminating the risk of pregnancy, especially in relation to female participants.

*Emma: Yeah they told me that to be careful with him [when asked if staff gave advice]*

*Researcher: What do you mean 'careful'?*

*Emma: Like only do things (of a sexual nature) that you want to do.*

*Kerry: Staff said that because he has them [warts] we must not undress or go naked when he has them. Because they said that I may catch them. So staff said that if we do it then he has to wear a condom. Yeah so I said to staff that I understand and all this.*

It could be seen as empowering to female participants to be in control of their own fertility. However, due to the perceived concerns staff may have regarding pregnancy (see 5.2.2), this could also be seen as possible control as most contraception provided to the participants was 'long-term', such as implants or injections rather than the pill or condoms. Carrie was on the implant but not sexually active. This suggested that staff may have consciously or unconsciously limited participants' ability to make decisions regarding their contraception, decreasing their autonomy and therefore limiting their ability to meet their 'self-esteem needs'. Also, staff did not appear to be providing any support to Carrie and Joe regarding their inability to engage in penetrative sex, in this case focussing on contraception rather than developing intimacy. Support from staff to engage in sexual relationships could assist couples in increasing intimacy, as a



physical relationship was shown to enhance intimacy for couples with existing emotional bonds (Jamieson, 1999) and intimacy has been considered important for secure attachments (Mikulincer, 1996). However, it was positive that some staff considered sex a 'need' for people with learning disabilities. Considering Maslow theory, an intimate sexual relationship could assist participants in meeting their 'love and belonging needs'. It was unclear what advice was given to male participants regarding sexual relationships as they were reluctant to discuss this in the interviews with the exception of Liam, although all of the male participants confirmed they had received support in this area at some point in their lives.

For the female participants the advice from staff was aimed more at addressing emotional needs, especially around dealing with issues and conflicts within the relationship. This support appeared empowering to couples as it helped them to address issues within their relationships which they may have found difficult without support, possibly strengthening and maintaining their relationships. For some participants, such as Caroline, staff appeared in the role of mediator assisting the couple in addressing issues and resolving arguments.

*Caroline: If we say for instance we have an argument or something the staff would support us and would know what to do or say or whatever.*

Staff provided emotional support and practical advice to participants, taking on the role of social care professionals who were providing advice, but also bound by their duty of care to ensure participants were safe. However, on some occasions it was suggested that staff went beyond what was required professionally by engaging in conversations which were more typical among peers than paid professionals, while still remaining professionally appropriate. They provided advice on topics outside of their job role including initiation of relationships and flirting. This appeared to be a positive aspect of the staff/participant relationship as some individuals had no (or insufficient) peers to engage with like this and it provided a safe place to discuss sensitive topics.

*Emma: When he left, when he went back to his old place, I told the staff that I did fancy him and that I wanted to go out with him.*

*Caroline: I said to one of the staff 'what should I do I don't know what to do'? And she just said 'act normally and everything'.*

### **Initiation of relationships**

Staff provided emotional and practical support to participants in relationships. However,

for some participants such as Alan, staff went beyond this and played an active role in the initiation of their relationship. It was uncertain whether Alan would have pursued his relationship without this initial encouragement.

*Researcher: So you came back to the house. Did you sort of decide between you that you were going to be a couple?*

*Alan: No, not for some time. They wanted us to try it out, the staff did.*

*Researcher: Oh right. What the staff wanted you to try it out. What did they say?*

*Alan: They said how did you get on in X [local town he went to on a date]? And they said do you want to do it again?*

Staff also played an active role in the development of the relationship between Mary and Gary. The gatekeeper informed me when initially discussing the research that staff were responsible for organising their dates in terms of logistics, supporting Mary to call Gary as she had no personal phone, collecting Mary from his home and actually attending dates outside the home with the couple. Staff stated that Mary would have not been able to develop a relationship without this level of support from her staff team. Staff only seemed to provide support to develop relationships where participants had higher support needs, whereas those with lower support needs did not require this level of support. This emphasised that due to their embodied reality of their learning disability, such as poor communication and organisational skills, some participants would have been unable to form a relationship without staff support.

In summary, staff appeared to act as facilitators of the relationships by providing individuals with guidance and information, which enabled them to experience safe and happy relationships. Staff had a key role in supporting individuals to meet their 'love and belonging needs'. Maslow described love as a 'higher psychological need' in contrast to attachment theory which considered it a 'basic need' (Bowlby, 1973). While it may be considered by attachment theory as a 'basic need', the reality appeared that some participants, due to the embodied reality of their learning disability, experienced problems negotiating the sometimes complex process involved with establishing and maintaining a relationship. It could be suggested that this 'need' would not have been attained without staff facilitation. Although not explicitly discussed, staff possibly influenced the type of partner participants had. It was possible that, in order to protect participants, they discouraged poor partners and encouraged positive potential partners as they were responsible for their 'safety and security needs' due to a duty of care to protect vulnerable people in their care. All of the participants who were not living with a partner were in relationships with individuals supported by the same organisation. This

suggested that staff might have encouraged these relationships as the person was known to be 'safe' and thus individuals could be protected.

Staff often assumed a parental role, providing factual advice to those they were responsible for, but also sometimes took on the role of a confidante providing informal advice on issues such as dating. This partly relates back to participants' isolation and lack of companionship: staff were fulfilling these roles, whereas for people without a learning disability this would possibly be the role of family and friends. Staff had a more powerful role in situations where participants were more reliant on staff for information. Staff also had significant power in terms of the organisational aspects of the relationships for people with higher support needs as they were more likely to rely on staff in order to maintain the relationship. The success of the relationship could be determined by the commitment of the staff team, not the individuals in the relationship. Staff appeared to be facilitators in determining whether people with higher support needs made loving attachments and met their 'love and belonging needs'.

## **5.4 Theme Four: Familial and Societal influences on Relationships**

The fourth theme identified was the influence of the family and society. The three sub-themes that appeared to be significant in terms of the influence of family and society were:

- Family Influence on Relationship Patterns

- Negative Familial Influence

- Societal Influence

### **5.4.1 Sub-theme One: Family Influence on Relationship Patterns**

The relationship between participants and their families was discussed in part in Chapter 4 in reference to issues such as abandonment and rejection. Unlike attachment theory (see Section 2.3.5), Maslow made no reference to the impact of family relationships patterns on relationships but, in order to provide a holistic picture, this Section discusses how their family relationships influenced their relationships with partners at the time of the interviews.

#### **Parents' relationship's influence on current relationship**

Four participants (Emma and Liam; Joe and Carrie) discussed their parents' relationship in detail and the impact it had on their own relationships. They were all

younger participants who had a high level of exposure to their original family environment, living at home until adulthood. Emma was the only participant to state that she came from a happy and stable family where she believed there were no rows between her parents. She recalled that her parents were in a long and happy marriage.

*Researcher: How did they [parents] show it [that they were happy in the relationship] to each other?*

*Emma: Because they were speaking to one another showed they were happy. They didn't fight.*

Liam, Carrie and Joe all came from families where they claimed arguments were a frequent occurrence and none of them wanted this pattern replicated in their own relationships. According to Liam, his parents' relationship was not a happy one and they argued frequently prior to divorcing when Liam was a teenager. Liam was unhappy about the divorce, but he also described how he was deeply affected by the disagreements.

*Researcher: Do you remember if they argued?*

*Liam: Yeah I do actually every time.*

*Researcher: What, when they were together?*

*Liam: Yeah together all the time, arguing all the time*

Liam reported a good relationship with his mother and sister, who both played an important role in his life. Liam did not feel that his parents' divorce had a negative impact on his ability to form and maintain relationships, stressing that his relationship would be different to his parents. Liam and Emma reported minimal disagreements. Liam suggested the key to a happy relationship was not to argue and to address issues through good communication and compromise. Liam and Emma's responses implied they had a high level of social skills and appeared able to compromise and negotiate conflict both in their own relationship and with others as discussed further in Section 5.3.

*Researcher: Do you think their divorce had made you think differently about getting married or not?*

*Liam: Not really*

*Researcher: No?*

*Liam: Keep together, me and Emma will stay together all the time.*

*Researcher: So do you think your relationship your marriage will be different?*

*Liam: Yeah, yeah!*

*Researcher: How are you going to make sure it is different?*

*Emma and Liam: Don't argue. Try not to argue with each other*

Carrie had also experienced her parents' divorce in her teens. She recalled that there were frequent arguments prior to the divorce which she did not wish to be replicated in her own relationship with Joe although feared this was a possibility. Joe stated that his parents also argued frequently. Joe disliked this and did not want to repeat the pattern in his own relationships. It appeared in the interviews that their fears may have been confirmed as both Carrie and Joe admitted to rowing frequently, suggesting there was a possibility that they were developing a similar relationship.

*Researcher: You said the best thing about marriage is getting to make up. Do you row?*

*Carrie: Not all the time but now and again.*

*Researcher: What kind of things do you row about?*

*Carrie: Small things.*

The difference between Joe's parents' relationship and the parents of Liam and Carrie was that his parents did not become separated. This may have provided Joe with a model for a relationship where it is acceptable for partners to frequently row if there is an understanding that they still love each other and are committed to remaining in the relationship. Joe did not see his parent's relationship as ideal and cited his Grandfather's relationship as a role model and wanted to have a similar relationship. Joe chose the same church as his Grandparents to get married in and this appeared symbolic for him.

*Joe: Because I copied him to get married (same church).*

*Researcher: What was it about them that you copied? Was it just that you got married in the same church or did you want to copy the marriage that they had?*

*Joe: What they had.*

*Researcher: What did you like about it? [Grandparents' marriage]*

*Joe: They was very strong and they stayed strong.*

*Carrie: And grounded, they didn't argue, didn't fight.*

Despite their arguments, Carrie and Joe's relationship felt very 'real and genuine' and there was clear affection, love and a willingness to work on their relationship. Both grew up in families where there was tension yet they appeared comfortable with the level of tension in their own relationship.

Kerry and Dean's relationship, like Joe and Carrie's, also felt 'real and genuine' and they admitted that, despite arguing, they were able to communicate and address this issue.

*Kerry: Just talk to each other and apologise to each other and say sorry and we just end it, forget about that. We are alright in the end aren't we? [to Dean]*

Kerry had experienced an abusive and negligent relationship with her parents and had not replicated this (based on her accounts) in her relationships. Kerry was involved in self-advocacy organisations and appeared outspoken and autonomous, claiming she would not tolerate abuse in her relationships and was able to assert herself when required. This appeared to be related to her past and unwillingness to tolerate further abuse.

#### **5.4.2 Sub-theme Two: Negative Familial Influence**

Some participants had experienced abuse within the family setting. However, since this aspect of their background was discussed in the exploratory thematic analysis (see Chapter 4), this Section focuses on other negative aspects of family influence such as control.

##### **Control and Autonomy**

Some participants discussed the control their parents exerted over them and the lack of autonomy they experienced within their lives. This control ranged from controlling people's movements to controlling where they lived. Since she had been sent away from home, Caroline spent her life in institutions of some description: first boarding school; working in a laundry; a convent and then various care homes. Caroline claimed to have had little autonomy and said her mother chose these places for her. She disliked most of the places she was sent to but appeared unable to challenge her mother's authority.

*Caroline: My mum thought it was a good idea that I lived there [convent]. I didn't like it at the convent as it was really religious.*

Caroline's acceptance and placidity was unsurprising as twenty plus years ago there were fewer opportunities available to people with learning disabilities, little focus on individuals' empowerment or rights and few advocacy/disability groups. Caroline's mother appeared to have controlled aspects of Caroline's life under the premise that she was acting in her daughter's best interests, fearing there was no place in the world for her daughter so she attempted the best she could to find one for her. However, that was not how Caroline interpreted her actions. Caroline's mother's actions also

suggested that she may have thought Caroline lacked the autonomy to make her own choices. Her mother's actions may have acted as a potential barrier to Caroline's ascension of Maslow's hierarchy.

Mary stated that her parents restricted her actions while living within the family home. It could be inferred that Mary was empowered by the freedom that her current home provided as opposed to living with family where Mary stated she was allowed to have partners who could visit her flat unchaperoned, unlike when she was living with her family who did not allow her to engage in relationships. It appeared that Mary, like Caroline, had never challenged her family's authority. However, this may have been due to her ethnic background, which places significant emphasis on respecting elders.

*Researcher: When you lived with your family would you have been allowed to have a boy in your room?*

*Mary: Not allowed*

*Researcher: You said they [parents] wouldn't have let boys in your room.*

*Mary: No you don't do this.*

*Researcher: Ok, so you used to live with mum and dad and they did not allow boys in the home. Did you ever ask if a boy could come over?*

*Mary: No, not much really*

*Researcher: Would mum and dad have allowed you to have a boyfriend?*

*Mary: Oh no, it's not allowed really*

Despite the influence of her family, Mary was able to increase her autonomy and pursue a relationship with staff support. Mary had recognised that her parents no longer had authority over her relationships, which was empowering. However, from her comments, it did not appear that her parents recognised this relationship as serious. They had never met Gary and staff confirmed that her parents were aware of him but they did not 'see him' as a 'real' boyfriend. Mary saw her relationship with Gary as more important than her relationship with her family. This appeared to be related to the amount of contact she had with Gary.

*Mary: I like Gary - he is better [than parents].*

*Researcher: You like Gary - he is better. Why do you like Gary better?*

*Mary: He is more often [seen more often]. He comes here every day isn't it?*

This was in sharp contrast to Carrie, who was very open in discussing relationships with her mother and her mother was happy for her to date as a teenager.

*Carrie: She had no idea. I said I was going out with a friend to the cinema, then when I can home from school she said 'right how did you get on your date'? I said he is really sexy and hot.*

*Researcher: OK so was your mum pleased?*

*Carrie: Yeah she was fine*

This was unsurprising considering there is approximately fifteen years' age difference between the two women. Within the past two decades there had been changes in attitudes towards the rights and perception of adults with learning disabilities (as discussed in Chapter 6) and in society as a whole (as discussed in Section 2.2). Mary is also from an ethnic minority which probably holds more traditional values than western society, thereby making it unlikely that Mary's family would be as accepting as Carrie's regarding relationships. Joe's family actively encouraged him to be autonomous and to engage in a relationship.

*Joe: I told my brother and he told mum and dad. [that he had girlfriends]*

*Researcher: What did they think?*

*Joe: Get in there boy!*

In summary, the participants' relationships with their parents were significant to the later development of their relationships with others. This appeared more apparent in cases where participants had spent extended periods living within the family unit.

Parents/family background appeared to have an impact on aspects of participants' relationships with partners, such as determining the level of acceptable conflict and physical affection. As outlined in attachment theory (Hazan and Shaver, 1987), participants who originated from families which displayed happy, affectionate relationships appeared to have happier, more affectionate, relationships with others later. All of the partners who came from families where there was conflict between parents were keen not to replicate this in their own relationships. A negative parental relationship did not act as a barrier to forming a relationship, but it could possibly involve more dedication and effort from participants to ensure it was not replicated in their own relationships.

Younger participants were less likely to experience families who were controlling. Their parents were more likely to encourage their children to be autonomous and have similar life experiences to their non-disabled peers, such as engaging in relationships and offering advice and support. Controlling families in this group were not barriers to relationships once people had moved from home. Staff (who went on to have more influence over relationships than families), empowered people to be autonomous and engage in relationships if they desired and did not usually replicate these controls. This



highlighted the significance of families in the attainment of 'love and belonging needs'; controlling families could possibly stop people reaching this level of Maslow's hierarchy. Most couples appeared to select partners with a similar family background or dynamics which, while probably an unconscious choice, suggested a level of comfort and familiarity.

### **5.4.3 Sub-theme Three - Societal Influence**

#### **Peer Pressure**

Social status was linked to having a partner, which correlated to some extent with Maslow's theory (1943). Specifically for younger participants, there was appeared to be pressure if a partner had not been found. It appeared that this pressure was similar to what is commonly raised by young people without a learning disability, to 'fit in' with their peers and applied more specifically to young women. Emma felt pressure to have a partner. This pressure came from her college friends and she was the last to have a partner.

*Emma: Because it is nice telling your friends that you have a partner, especially, like, if they have one and now you have got one. Because you are letting them know that you have got one now [boyfriend]. So you are not left out.*

It did not seem that the older female participants felt this pressure, as both Caroline and Mary were in their forties when they first had a partner and neither person reported feeling this way. Male participants did not specifically identify in interviews that they felt pressure to have a partner but some stated that they were keen for peers to know they had partners. This implied that they may have felt the same pressure as females but did not disclose this.

*Liam: I tell my friends I have a girlfriend about that I did. I told them.*

*Researcher: So you like to tell all of your friends that you have a girlfriend and you like to tell all your friends that you have a partner.*

*Liam: Oh yes!*

#### **Social Mirroring**

Section 5.4.1 explored how parental/familial behaviour influenced the relationships of participants. However, this was not the only factor influencing how participants interacted within a relationship. There was possibly an element of mirroring cultural norms among participants, taking their cues regarding how to behave in relationships

from sources like the media. Social mirroring could be considered a form of aspiration, a desire to attain the higher levels of Maslow's hierarchy including social status and self-respect and it appeared that having a spouse/partner was a facilitator to achieving this.

Almost all of the participants discussed their love for television and soap operas particularly. These programmes often display grand romantic gestures such as men proposing on bended knees. Alan claimed it was his decision to ask Ann to marry him. However, as discussed in Section 5.3.3, Alan required prompting and direct support from staff to arrange a date. It was possible that Alan saw images of proposals in the media and mirrored these elements such as going on one knee and having a ring. It was unclear if Alan chose to marry Ann solely because he loved her or if there was an element of mirroring what he saw on television, having learnt that marriage was what dating couples did next or to attain the status conferred by society for being married. The reason for this interpretation was that he was unable to give a response as to why he married Ann. It was possible he did not understand the question and he was asked again in a different way:

*Researcher: So what is it about Ann that you think, you know, made you want to marry her?*

*Alan: I don't know. You know it's hard to tell.*

It was also likely that Mary was displaying some element of social mirroring regarding the significance she gave to Valentine's Day. Mary mentioned this day numerous times and considered this the day where couples were romantic. Although this is reflective of how people without a learning disability also view Valentine's Day, Mary only seemed to equate romance with this day. This suggested an element of social mirroring where, like Alan, she behaved in this way because society and the media suggest that she should. This was not to suggest that she did not want to engage in this (or enjoy it), however it felt less organic and more 'learnt'. Mary may have unconsciously utilised Valentine's Day to demonstrate to society that she held the socially valued role of 'girlfriend' by engaging in a 'romantic meal' publicly with Gary.

*Researcher: You have spoken a lot about Valentine's Day. Is it important to you?*

*Mary: Yeah*

*Researcher: Why?*

*Mary: Because I have a special dinner for the evening meal.*

Despite differences in dating patterns (see 5.1.1) compared to adults without a learning disability, the participants appeared to conform to social stereotypes regarding some

dating patterns, like the man paying for the date which, again, may have been due to social mirroring. Caroline confirmed that John was chivalrous and paid for the meal on their dates.

*Caroline: He treated me. We went to another café and he treated me to some lunch and of course we both had some and we did that quite a few times and kindly paid for me for that.*

Men were more likely to initiate relationships, which was possibly due to mirroring cultural norms. Chapter 4 identified that various participants had grown up within some form of institution and, therefore, may have had limited exposure to the cultural norms of how to behave within relationship and this, therefore, may result in social mirroring, where participants seek information from other sources such as television with less balancing from experiential or exposure to real-life relationships.

### **Pride**

Almost all of the participants indicated that they enjoyed telling people they were married, engaged or with a partner. There was a great pride in this for almost all of the participants and this seemed to be more apparent for older participants and those with higher support needs. Relationships and marriage were traditionally 'off limits' for people with learning disabilities, both in terms of marriage and in terms of co-habitation. Being part of a relationship suggested a sense of normality and being an ordinary member of society, also confirming that they, too, were special and wanted by someone.

The ring was of great significance to both Caroline and Peter. It is possible that participants saw the ring as an outward symbol of acceptance and status, a way of signifying to the world that they were 'just like other people' and special to someone. For Caroline obtaining a ring appeared to be her prime motivator for becoming engaged. This appeared to be more important to Caroline than a marriage. When asked what you would like most about getting married Caroline said:

*Caroline: The ring, I suppose so yeah....I think it [the relationship] would be the same except that maybe you could sometimes show your ring off and say 'I am engaged to get married. I don't know, you might feel a bit more, you might feel as proud as punch (when asked how she would feel if engaged).*

The ring was also of significance to Peter, who liked others to see his wedding ring, possibly considering this a way to signify to the world that he was married and had

someone to love him/want him. This suggested that Peter and Caroline wanted others to see them in the socially valued role of spouse, which would increase their status in society by demonstrating they could attain this life goal, which may increase their self-esteem.

*Researcher: What does it feel like saying you are married?*

*Peter: I like it*

Joe and Carrie also liked to tell people they were married. However, when explored further it appeared that Carrie and Joe were more excited about being married than others' perception of them as a married couple. They had pride in being married but their future together appeared more important than social perception.

*Researcher: How does it make you feel Joe to tell people you are married?*

*Joe: Happy*

*Researcher: Makes you happy?*

*Joe: Excited*

*Researcher: Yeah. What are you excited about?*

*Joe: Getting married (bit I can't hear) my life*

*Carrie: About our future ahead*

However, it could be argued there was a similar symbolism in Joe wanting to get married in the same church as his grandfather. He may have wanted to be perceived by others as similar to his grandfather in as many ways as possible. Also, having a large wedding in this church was possibly a way to demonstrate to society that they were 'just like everyone else'. Their families paid for their wedding, suggesting their families were keen to support and encourage this. It was possible that by doing this they also lessened any residual stigma they may have felt at having a child with a learning disability and saw the wedding as an opportunity to demonstrate to society that their children were no different to any other young couple in love. Their families may have perceived the weddings as a means to increase social status by demonstrating their children could achieve similar life goals as those without disabilities.

All of the participants, to varying degrees, were aware of their disability and that they differed to some extent from the general population. Some were more accepting of this than others. Younger participants such as Liam and Emma and Carrie and Joe referred openly to their disability and appeared more accepting compared to some older participants such as Alan. It is possible they were young enough to have absorbed a

'whatever' apathetic attitude as have many other youth without learning disabilities, possibly giving them the psychological freedom to just enjoy being themselves. All of the participants liked to signify to others that they had a significant other: this was possibly a way of demonstrating to society that someone wanted them and the ring or large wedding was an outward symbol of this. The increase in 'self-esteem needs' of having a partner appeared important, however, unlike the view proposed by Maslow, participants placed greater significance on love in relationships rather than the historical view of increasing social status.

## **5.5 Summary of Hermeneutic Phenomenological Analysis**

The most significant finding of the hermeneutic phenomenological analysis was that the participants both wanted and valued a partner who loved them; this could be defined as making a secure attachment to another person (Bowlby, 1979) or as described by Maslow (1943) a wish to meet their 'love and belonging needs'. Maslow (1943) described a historical view of relationships which placed limited significance on love and primary significance on relationships as a process to increase social status and 'self-esteem needs'. This was opposed to modern descriptions of relationships which focus on love and intimacy (Graham, 2011). Having a partner was a source of pride for all of the participants and being part of a couple permitted them to engage in activities which were not typical for people with learning disabilities, such as being engaged and getting married, romantic restaurant meals and having this witnessed by society. It could be argued that reducing stigma would be a more appropriate term than social status to include on Maslow's hierarchy for people with learning disabilities, due to the stigma they experience (as outlined in Sections 2.2 and 2.4) and being seen in a socially valued role could assist in reducing this. It could be argued that, due to their learning disability, participants had a reduced understanding of abstract concepts such as 'social status'. However, all of the participants, to some extent, demonstrated they were aware of the social status afforded to being a 'spouse/partner'. This was evidenced by the pride they felt by being in a relationships and the social pressure some participants experienced when they were single to be in a relationship. Participants' relationships did not appear representative of Maslow's description of relationships, as love and intimacy appeared more significant to participants than social status and recognition.

Individuals who were securely attached experienced longer loving relationships in adulthood (Hazan and Shaver, 1987). All of the participants appeared able to form a loving attachment to another person despite the possible challenges they may have

experienced in regards to attachment as outlined in Chapter 4. People valued an exclusive reciprocal relationship with a significant other, enjoyed being special to someone, having someone to share their lives with and being wanted by someone who cared about them. The most valued aspect of being in a relationship appeared to be the companionship it provided. This related to its intimacy and suggested a partner provided more than just a 'presence'. Physical affection was valued by all of the participants, although only some of the couples (usually younger ones) engaged in sexual intercourse. All of the couples desired affection which related to Maslow's 'love and belonging needs', but sex appeared less important. This suggested that it was affection, as opposed to sex, which was a 'basic need'. Affection is important in Maslow's theory but is considered a 'higher psychological need', whereas attachment theory considered it a basic component for healthy development (Ainsworth *et al.*, 1978). Affection was possibly used to communicate that a person was important, and this was significant especially where individuals had experienced abuse or rejection as it appeared to have a reparative quality and increased intimacy. Physical attraction was important in relationships, especially for initially attracting someone, but the emotional connection became more significant as the relationship developed. Attraction was not clearly defined by a set of pre-defined desirable physical attributes. 'Nice' and other associated traits (such as friendly/kind) were valued highest, unsurprising when considering participants' histories of abuse and discrimination.

Individuals still experienced restrictions in their lives from a range of sources which included housemates, staff and family members. Restrictions from staff were often imposed, not necessarily to be punitive but to protect individuals as staff were often in conflicting roles. They were obligated both to protect their 'safety and security needs' while also developing autonomy and independence. Overall, staff were supportive of relationships and provided participants with support and guidance surrounding all aspects of their relationships, helping them to become more autonomous but taking direct action when safety was compromised. Due to the participants' isolation, staff were fulfilling these roles, whereas for individuals without a learning disability family and friends would be more likely to fulfil this role. It was a fine balancing act to ensure that staff remained supportive without being controlling or overprotective. Staff had the power to 'make or break' relationships, as it would be challenging for people with higher support needs to form and maintain relationships independently. This highlighted the need for staff teams to be committed to fulfilling all levels of Maslow's hierarchy, not just the basic levels.

Despite living in the wider community, the participants remained often remained

segregated from it which limited their opportunity to meet potential partners. Couples were only formed within environments exclusively for people with a learning disability. Younger participants had increased opportunities and less experience of institutionalisation. As a result, younger participants were more likely to have had a relationship with a member of the opposite sex at a younger age, engage in a sexual relationship and for both partners to have had higher life goal expectations such as living alone with a partner.

It was evident how different the experiences of older participants were from the younger, but what was common to all is that they were being supported by the welfare state. Since support providers' decisions and actions are subject to scrutiny, the next Chapter explores the changing social context and reflects upon its impact on participants.

## **Chapter 6- Recognising Needs and Rights: Key Developments in Policy, Practice and Attitudes**

The previous Chapter identified that people with learning disabilities still face challenges in the formation and maintenance of relationships, and attaining the 'needs' outlined in Maslow's hierarchy (1943). Despite these challenges they were all able to form loving attachments with a partner. However, the participants with learning disabilities were still more likely to be isolated from mainstream society than people without a learning disability. The situation was more optimistic for younger individuals. Physical attraction was important in fostering the initial attraction in a potential partner, but it was a 'nice' personality that maintained the relationship, accompanied by the companionship and pride associated with having a partner. Physical affection was valued and often viewed as a way to reinforce that a person was wanted, loved and special to someone. Some participants had experienced loss and rejection and affection appeared reparative.

Section 2.2 examined the social, historical and cultural influences on sexuality and relationships for people with learning disabilities; this Chapter will focus on how key developments in policy and practice have influenced the attitudes towards people with learning disabilities as outlined in Section 2.2 and extrapolates these to my participants to provide an additional historical context. As outlined in Table 5, Van Manen (1990) argued that context was central in understanding phenomena such as the social historical perspectives. Section 6.1 includes a brief history of people with learning disabilities throughout the nineteenth, twentieth and twenty first centuries, providing some context for the findings identified in Chapter 5. Sections 6.2 - 6.2.5 examine how the policies, practices and attitudes discussed in Section 6.1 have influenced participants' lives and choices in relation to partner selection. These Sections also identify how changes in policy, practice and attitudes have acted as either barriers or facilitators to relationships.

### **6.1 Key developments affecting people with learning disabilities in the nineteenth, twentieth and twenty first centuries**

Table 9 displays the major pieces of legislation, reports and landmarks within England in relation to adults with learning disabilities since the 1840s to recent times. The content displayed for each of them reflects the attitudes of society at the time towards people with learning disabilities. This timescale was selected as it demonstrates how



people with a learning disability were perceived and attitudes and policies changed over the course of both the participants' and their parents' lifetimes. Only UK or English specific legislation, reports or landmarks were considered, as all of the participants grew up within England and under this political system. The construction of this Table identifies how many changes in policy, legislation and attitudes the participants in this research had experienced in their lifetimes. The major changes and developments focused on areas such as where people lived, personal freedoms, civil liberties, inclusion in society, authority to challenge poor practice/abuse and the ability to initiate change.

Table 9 presents four aspects of the key legislation, policy changes, reports or landmarks in relation to social care and the support provided to people with learning disabilities:

- The date it was established/introduced/made law
- The title/definition
- Its impact
- An approximation of key events in participants' lives – an approximation of both participants' and their parents' birth and participants' entry into services (note a service entry was not available for all of the participants - it was unclear when Alan, Dean and Peter became known to support services). Staffs' birth and entry into the work force was also included as this demonstrated how the key legislation, policy changes, reports or landmarks may have influenced their views regarding people with learning disabilities. Staff were split into older staff (over 35 years old) and younger staff (under 35 years old).

The terms 'idiot', 'natural fool', 'feeble-minded', 'imbecile', 'mental defective', 'mental deficiency', 'mentally retarded' and 'mentally handicapped' all refer to people with learning disabilities and are used interchangeably throughout this Table, based on the language used in the Act/policy which reflected the attitude within society at the time towards people with learning disabilities.

**Table 9: Timeline of Key Legislation/ Policy Changes/ Reports/ Landmarks**

Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
1834	Poor Law Amendment Act	Until this Act was passed poor relief was distributed by the parish to those in need. This could be provided outside of the 'workhouse': however, this Act discouraged the provision of relief outside the workhouse, which resulted in an increase in the number of workhouses constructed. The workhouses' conditions were harsh (Fowler, 2007). People with learning disabilities who lived in this period were often defined as 'village idiots' and would have most likely have entered a workhouse, seen as dependants and to be pitied.	
1845	Lunacy Act	Under this Act the Government had to provide psychiatric hospitals for the mentally unwell. People with learning disabilities were often defined as 'natural fools', having been so since birth, and the mentally ill were seen as 'lunatics' with the disturbance occurring after birth (Wright and Digby, 1996). However, it was thought that many people with learning disabilities resided in such hospitals (Ryan and Thomas, 1987). This definition of a learning disability being inherited produced a fear regarding the procreation of people with learning disabilities, fearing they would also have a 'mentally defective child'.	
1886	Idiots Act	This was the first Act which focused on the education of 'idiots'. The Act aimed to provide care, education and training of idiots and imbeciles.	
1869	Eugenic Movement develops	Galton (1869) identified the notion that societies could be improved through removing undesirable, inherited characteristics. There was a fear that people with learning disabilities would pollute the human race if they procreated by increasing the number of people born with disabilities. During this period there was a call for the sterilization of women with learning disabilities but it was rejected by the UK Government (Porter 1999).	
1904-1908	The Royal Commission on the Care and Control of the Feeble-Minded was established	Its purpose was to review the methods which dealt with 'idiots', 'epileptics', 'imbeciles', 'feeble-minded', or any 'mentally defective' persons who could not be classified under the Lunacy Laws. The aim was to ensure mentally defective individuals' wellbeing.	

Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
1908	Royal Commission on the Care and Control of the Feeble-minded - Radnor Report	The report advocated for people defined as 'mentally defective' to be separated into colonies away from society (Ryan and Thomas, 1987). The report stated that mental defectiveness was inherited which the Eugenics Movement supported.	Alan's Parents born in early 1900s
1913 and 1927	Mental Deficiency Act Mental Deficiency (Amendment) Act	<p>This Act divided mental defectiveness into three categories: 'idiots', 'imbeciles', and 'feeble-minded'. People defined as mentally defective were deemed unable to live independently. Colonies were set up to house these individuals, often in remote country locations and all facilities were situated on site so individuals did not associate with the wider community. Once people moved to these colonies they did not return to mainstream society (Gilbert, 2009).</p> <p>There was an amendment to the Act which acknowledged that mental deficiency could be caused as a result of an accident or illness, which was a radical notion at the time.</p> <p>Section 56 of the Act made it illegal to have sex with a woman under care of / receiving treatment within an institution.</p>	<p>The parents of Caroline, John and Mary were born during this period</p> <p>Mary's parents were most likely born in Asia</p>
1927	Buck v Bell (USA)	In the USA, Supreme Court Justice Oliver Wendell Holmes Jr. upheld the case for the compulsory sterilisation of a woman with learning disabilities after she had an illegitimate child (later thought to be because of rape by a family member). The judge stated "three generations of imbeciles was enough". This case was used a defence for sterilisation of people with learning disabilities in both the USA and Europe including at the Nuremburg trials by Nazi doctors (Oberman, 2010).	
1946	The National Association of Parents of Backward Children formed	This was started by a mother of a 'backwards child', Judy Fryd, who wrote to a magazine asking for other parents to contact her regarding their anger at a lack of services for these children. This group was the precursor for The Royal Mencap Society.	

Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
1948	Welfare State and National Assistance Act	Under the Welfare State the Poor Laws were removed. Colonies were renamed as hospitals. However regimes remained harsh and no attempt at social integration was made. Sexes remain separated. Care for the 'mentally handicapped' (as they were now called) was the responsibility of mental health departments.	Alan born (approx.)
1956	Sexual Offences Act	This made it illegal to have unlawful sexual relationships with a female defined as 'mentally defective' or the man 'knows to be an idiot or imbecile'	It is estimated that the younger participants' parents were born in this period between 1955-1965
1957	The Report of the 1954-57 Royal Commission on the Law relating to Mental Illness and Mental Deficiency (the Percy Report)	This was one of the first reports which proposed a community-based approach to care for people with learning disabilities as opposed to care within segregated hospitals (Barber, 2012)	
1959	Mental Health Act	This repealed any existing mental deficiency Acts. Patients entered on a voluntary basis, unless sectioned because they were deemed a threat to themselves or others, and were free to leave if they desired.	Caroline, John and Peter born (approx.) John in child services since childhood

Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
1961	Publication of Erving Goffman's – <i>Asylums: Essays on the Social Situation of Mental Patients and Other Inmates</i>	This was a key text in the development of deinstitutionalisation, highlighting how strict regimes in hospitals were established to control patients' behaviour. Goffman worked undercover in a large psychiatric hospital in the USA and although the book was not based on the UK system it was influential in changing how UK society viewed 'asylums'.	Older Staff aged between 35-60 years born approximately in this period through to the mid-1970s
1963	Mencap opened the National Society's new hostel and training workshop	This was the first training centre of its kind in the UK for people with learning disabilities	
1966	Formation of Mencap's Gateway Club	Gateway clubs open offering sports and leisure opportunities for people with learning disabilities	
1969	Howe Report - Report of the Committee of Enquiry into Ely Hospital	This report identified the poor conditions people were living in, how their human rights were not respected and staff behaviour was custodial. There was a public outcry when the report was published and outrage regarding the level of care these vulnerable people received. Public and political opinion began to change regarding the institutions' ability to care for people with learning disabilities. It was felt that standards in therapeutic care were declining in institutions and a number of committees were set up to explore concerns at three NHS hospitals which included Ely Hospital in Cardiff (Department of Health and Social Security, 1969), Farleigh Hospital (Department of Health and Social Security, 1971) and South Ockendon Hospital in south west Essex (Department of Health and Social Security, 1974).	Mary born (approx.) Mary may have been born in Asia
1970	The Chronically Sick and Disabled Persons Act	This was the first Act to state specific provisions to improve access and support for people with disabilities, ensuring local authorities provided housing. The aim of the Act was to give people with disabilities equal opportunities. It included a range of services government had to provide like adaptations to homes, meals at home or in a community centre, equal access to leisure and education and assistance with travel if required.	Alan moves into adult care services (approx.)

Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
1971	Government published White Paper ' <i>Better Services for the Mentally Handicapped</i> '	This set out the plans for 'Care in the Community' with the expectation that half of the hospital population of people with learning disabilities should be living in the community by 1991. The report outlined that people with learning disabilities should have active training and educational programmes; families with a child with a learning disability should receive support; the introduction of a broader range of residential services to meet individual's needs and a recommendation that hospitals become more homely and people were not segregated from their homes and families unnecessarily.	
1972	Wolfensberger published 'The principle of normalization in human services'	Wolfensberger was a key figure in the transformation of services for people with learning disabilities in the 1970-1990s, believing that people with learning disabilities should live as 'normal' a life as possible in their local communities. While he was not the only person at the time who held these views his thinking was extremely influential in the USA and UK. A decade later (1983) he changed the name of this principle to Social Role Valorisation (SRV) as he believed this was simpler, stating that people with learning disabilities should be seen in the same social roles as non-disabled adults such as a friend, partner or colleague. He believed that their lives would be improved via community integration not segregation. Normalisation itself was described as the 'most coherent ideology underpinning community care' (Smith and Brown, 1992, p. 686).	
1975	Publication of 'Fundamental principles of disability' which developed the 'social model of disability' by the Union of Physically Impaired Against Segregation' (UPIAS)	This highlighted the lack of control disabled people have over their lives and the power relationship with social care staff. They started to campaign for independent living and rights for disabled people	Kerry and Dean born (approx.)

Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
1975	Re D (A Minor) (Wardship: Sterilisation)	This was the case of an 11-year-old girl defined as 'mentally retarded'. Her mother requested that she be sterilised for reproductive reasons, but a judge who believed it would be a deprivation of a woman's right to reproduce rejected this request.	Younger staff born approximately in this period and up to the early 1990's.
1980	World Health Organisation published ' <i>International Classification of Impairments, Disabilities and Handicaps</i> '	This was defined as the Medical Model of Disability and defined disability in terms of 'impairment', 'handicap' and 'disability'. It focused on the individual's limitations and placed the 'problems' on the individual not society for not accommodating their needs. For example, it was the person's use of a wheelchair that was an issue rather than a lack of provision of a ramp.	Older staff possibly started work in this decade
1980s	First Centres for Independent Living (CILs) established	Set up by Hampshire Centre for Independent Living and Derbyshire Centre for Independent Living in 1984 demonstrating people with learning disabilities could live outside an institution and learn new skills to live independently.	Carrie and Emma born (approx.). Caroline moves into adult services (approx.)
1984	Registered Homes Act	Required small residential homes to be registered and for inspections to take place to protect residents. Codes of practice and standards for the accommodation/provision of care were introduced.	Kerry moves into child services (approx.)
1984	People First Established	Although other forms of self-advocacy had been developed in the 1960s and 70s prior to this date, People First was established by people with learning disabilities and supporters following an international conference on self-advocacy. People First remains one of the largest advocacy organisations with member groups throughout the UK.	Joe and Liam born (approx.)

Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
1988	Darenth Park Hospital Closes	Darenth Park opened in Dartford in Kent in 1878 as a residential school for 500 'mentally defective' children. By 1888 it housed 1000 mentally defective adults. By 1970 there were 1,500 people living there and the building was overcrowded and in poor condition. It was the first NHS learning disability hospital to close and its residents re-settled in the community, where they faced discrimination from the public. By August 1988 one thousand residents were resettled to other hospitals, hostels, small group homes and local facilities (Brend, 2008).	
1990	NHS and Community Care Act	The aim of this Act was to promote community care and the Government claimed this would lead to individuals receiving 'individually-tailored packages of care' and further deinstitutionalisation. The Act ensured that local authorities were responsible for the provision of care not the NHS.	
1990's	Introduction of Supported Living	Supported Living was developed by the by the National Development Team for Inclusion (NDTi) as an alternative to institutional care, where people had a separation between their care and accommodation. This provided people with secure tenancies instead of licences, affording more rights and enabled people to change support providers if they were unhappy with their service provision.	
1994	The Longcare Abuse Scandal and Inquiry	A leaked Buckinghamshire council report revealed that numerous people with learning disabilities had been beaten, neglected, drugged and raped at two residential homes in Buckinghamshire. Three perpetrators were brought to justice and received custodial sentence, but the main perpetrator committed suicide prior to standing trial. The Longcare Inquiry made 95 recommendations, three of which, in part, led to the introduction of the Public Interest Disclosure Act 1998 (the whistle-blowing act), the Youth Justice and Criminal Justice Act 1999 (covering achieving best evidence) and the Sexual Offences Act 2003' ( <i>Community Care</i> , 2007).	
1995	The Disability Discrimination Act	The Act made it illegal to discriminate against people on the grounds of disability	
1998	Human Rights Act	Formal legislation that outlined the rights that all human beings were entitled to and this included the right to 'family life' and the right to marry.	



Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
2000	Care Standards Act	The government body 'The National Care Standards Commission' was established to inspect registered and domiciliary care services to ensure they are meeting the minimum standards outlined by government to ensure quality.	Younger staff possibly started work in this decade
2001	Valuing People (DoH)	Sets out how the Government was to provide new opportunities for adults with learning disabilities in order to enable them to live full and independent lives as part of their local communities. This was focused on improving rights around key areas such as housing, support, employment and integration in the local community.	
2001	Person-centered planning (PCP's) introduced	As a result of <i>Valuing People</i> (2001), PCP's were adopted as government policy in the UK. This approach had been known prior to this but there was an increased application within services for people with learning disabilities following valuing people. The aim of PCPs was to focus on the person's needs, wants and wishes and to assist people to plan for their future. PCPs involve a 'circle of support' comprised of those close to the individual to assist them in achieving their goals.	
2005	Mental Capacity Act	Formal legislation that recognised individual's rights to make decisions, outlining that all people are deemed to have capacity unless proved otherwise and, if not, any decisions must be made in their best interest by an appropriate circle of support.	Younger Participants (Liam, Emma, Joe and Carrie) move into services (approx.)
2006	Cornwall Abuse Scandal	Widespread institutional abuse was identified of 200 people with learning disabilities living at a treatment centre in Falmouth and in 46 houses around Cornwall. This highlighted that, although most large scale NHS Learning disability hospitals had closed, some people with learning disabilities remained living in hospitals and experienced abuse. The situation was no better for those living in houses in Cornwall where residents, despite leaving the hospital, experienced widespread institutional abuse. This highlighted the poor care and support people with learning disabilities still risked facing.	

Date	Legislation/ Policy Changes/ Reports/ Landmarks	Impact	Participants Info (approx.).
2006	Government Report - ' <i>Our Health, Our Care, Our Say</i> '	One of the largest listening surveys which asked people what they wanted from their health and care services. People responded that they wanted individualised tailored care, care that helped people to take control of their lives.	Mary moves into services after living at home (approx.)
2009	<i>Valuing People Now</i> (DoH)	The follow up to <i>Valuing People</i> (2001) identified that not all of the outcomes in <i>Valuing People</i> had been achieved especially around health, employment, housing and relationships. The paper outlined that people with learning disabilities should have the chance to have relationships and get married if they desired.	
2009	Orchard Hill Hospital (Sutton) Closes	This was the last NHS hospital which housed people with learning disabilities to close. Its residents relocated back to the community under the care of local support providers.	
2010	Comprehensive spending review	The Conservative-led Government's comprehensive spending review identified that spending on councils in England was to be cut by at least 25% in real terms from 2011-15. '£23.7 billion of annual cuts will fall on disabled and older people and people living in poverty – 58% of all cuts. 24% of all cuts target the 1.9% of the population with the most severe impairments. 58% of all cuts target disabled people, older people needing support and people living in poverty' (Campaign for a Fair Society, 2012, p.1).	
2010	Equality Act	The Act streamlined and strengthen anti-discrimination legislation in the UK. The Act replaced a range of anti-discrimination legislation, including the Disability Discrimination Act.	
2012	Government publishes ' <i>Transforming care: A national response to Winterbourne View Hospital: Department of Health Review Final Report</i> '	An episode of the BBC's Panorama programme was aired on 31 <sup>st</sup> May 2011 and highlighted the abuse of people with learning disabilities in the privately operated hospital 'Winterbourne View'. The report identified how concerns were not listened to, that the management had allowed a culture of abuse to develop and staff were poorly trained and supervised. Members of staff were arrested and prosecuted. The programme highlighted how many people with learning disabilities now lived in private hospitals after NHS hospitals had closed.	

## **6.2 Key developments' influence on the lives of participants**

This Section explores how some of the key developments outlined in Table 9 affected the lives of the participants and possibly influenced their life choices, along with the options realistically available to the participants at the time. This Section will discuss five decades that are relevant to the ages of participants, which include:

- **1940 to 1959** - Emergence of the Welfare State
- **1960 to 1979** - Protectionism, Paternalism and Progression
- **1980 to 1999**- Thatcherism, Hospital Closures, Care in the Community and Emerging Presence
- **2000 to 2009** – ‘New Labour’, Investment in Public Services, Integration and Participation
- **2009 to Present** – Austerity, Global Recession, Spending Review, Cuts to Social Care and Public Services and Winterbourne View

### **6.2.1 1940 to 1959: Emergence of the Welfare State**

Since the introduction of the Welfare State in 1948 there have been significant changes in the way social care has been provided to people with learning disabilities. Under the 1948 Welfare State and National Assistance Act the isolated ‘lunatic asylums’ (or colonies as they were also referred to) became hospitals, but this changed little for the people who lived there. People with learning disabilities had little value in society and no real voice to challenge their oppressors. The regimes within the hospitals were harsh, people rarely left institutions and there was limited interaction between the sexes (French, 2010 and Abraham *et al.*, 2010). When the NHS took control of these institutions in 1948, people were viewed as patients, passive recipients of care by the state with no autonomy. Alan’s parents were born in the early 1900s: in this period there was significant social stigma towards having a child with a learning disability due to the perception of a learning disability as being inherited (Wright and Digby, 1996). Following the Mental Deficiency Act 1913 families were frequently advised by medical practitioners to place a child in an institution in the best interests of the child as the state could provide better care and facilities (Hreinsdottir *et al.*, 2006). Considering the issues surrounding maternal deprivation and institutional care outlined in Section 2.3.5, this possibly had serious implications for a child’s ability to form secure attachments (Bowlby, 1969). There was insufficient support for families who chose to keep a child at home and this was evidenced in the response to Judy Fryd’s magazine appeal to

parents regarding the lack of support and services available to 'backwards children' (Mencap, no date). Children, such as Alan, born in this period would most likely have been routinely placed in institutional care regardless of whether the family desired this or not. It was unclear if Alan had lived in such an environment as he discussed travelling by train when he was younger. However, people who lived in these environments rarely left the site unsupported. It was also possible that this occurred later in Alan's life as he was uncertain regarding dates.

Institutions for people within this period were closed communities, geographically isolated (French, 2010) and with limited external interaction. They were perceived by the public as caring communities for patients to receive the support they required by trained medical staff (Hreinsdottir *et al.*, 2006). Public opinion was that institutional care was the best option for such individuals until the 1954-57 report by the Royal Commission on the Law relating to Mental Illness and Mental Deficiency (the Percy Report) identified that a community-based approach to care for people with learning disabilities would be preferable to care within segregated hospitals (Barber, 2012). Concerns began to be raised that not all patients within the hospitals were receiving the care they required and that standards were falling. This era was witness to a significant change in the law and the start of social freedom for people with disabilities. Under the 1959 Mental Health Act patients who lived within learning disability hospitals became voluntary patients who could leave unless sectioned. However, it was unclear how many people with learning disabilities understood that they were free to leave the hospitals or what, if any, support was available to assist them to do so.

The social and political opinion within this period was that individuals with learning disabilities should not be encouraged to engage in relationships. This was due to a fear of pregnancy and the possible creation of more individuals with learning disabilities dependent on the state for support. There was a lack of opportunity for sexes to mix in order to prevent such occurrences (Brown, 1994, Howard and Handy, 2004). Older participants such as Alan were born in an era where it was acceptable for the Ministry of Health to declare in 1948 that people with learning disabilities were 'unfit for the responsibility of marriage'. It was highly probable that Alan was not encouraged to engage in relationships and that the state and public opinion supported this. This was possibly reflected in Alan's story where he shared how he was shy and reluctant to approach women. Even when attitudes had possibly changed it may have been difficult to forget how relationships were treated in the past. Under the 1956 Sexual Offences

Act, any woman classed as 'mentally defective' was excluded from a sexual relationship, regardless of whether she could consent or not, which today would be an infringement of her human rights (Human Rights Act, 1998). Maslow considered sex a basic human need, and interpreting the 1956 Act in light of Maslow's theory implies that legislators possibly saw women with learning disabilities as sub-human. Older participants would have grown up under this legislation, which could have affected how both they themselves and those supporting them would have viewed their sexual activity as possibly illegal. Older staff (over 35 years of age) would have also grown up in the same period, which could have had an impact on how they perceived relationships for people with learning disabilities. This mirrored the conservative attitudes to sexuality of the time for the wider population (see Section 2.2) where sex outside marriage and unwed motherhood remained taboo (Koffman, 2012).

Considering Maslow's hierarchy (1943) it was unlikely that individuals in institutional care were meeting even their most 'basic needs' as conditions were harsh and people had limited civil liberties (Abraham *et al.*, 2010). People were often segregated within single sex wards and removed from families and their communities resulting in little recognition of their 'love and belonging needs'. Limited civil liberties and poor conditions demonstrated how learning disability hospitals kept people at the lowest level of Maslow's hierarchy.

### **6.2.2 1960 to 1979: Protectionism, Paternalism and Progress**

Approximately ten years after Alan, Caroline, John and Peter were born and, although many people with learning disabilities remained in institutions, there was no longer the compulsory certification of individuals with learning disabilities, allowing people to be discharged from institutional care (Mental Health Act, 1959). This led to the start of a change in attitude towards people with learning disabilities, recognising that they were not sick or dangerous individuals who required 'locking up'. There were various high profile exposures of poor practice in learning disability hospitals. Between 1969 and 1974 committees were established to investigate concerns at three NHS hospitals: Ely Hospital in Cardiff, Farleigh Hospital in Bristol and South Ockendon Hospital in Essex (Quarmby, 2013). This was the start of a number of abuse cases involving care for people with learning disabilities which shocked society. The resulting public outcry led to both public and political opinion turning against these institutions and community integration became a priority. The horrific abuse disclosed within this period contributed

to a climate of protectionism surrounding adults with learning disabilities. Adults were perceived as children and their adult needs such as sex, and intimate relationships were neglected or discouraged by staff (Brown, 1994).

This protectionism was in contrast to the sexual revolution taking place within the 1960s for adults without learning disabilities as discussed in Section 2.2. However, in the 1960s attitudes towards people with learning disabilities began to change. Society began acknowledging that people with learning disabilities could learn new skills and professionals recognised that people required more mental and social stimulation than was provided in hospitals. Mencap began setting up training centres and the 'Gateway Clubs', which provided social and leisure opportunities (Mencap, no date). Both were progressive for their time but remained 'specialist learning disability services', still segregating individuals from the communities in which they now lived. Residential services in this period typically provided for many people and were understaffed.

It was unclear what social activities people engaged in. Caroline spoke of 'parties' organised within the home for residents as entertainment but it is unclear what access she had to her local community. Her story suggested that the large homes (often with several clustered together) formed a community although there is little information available about how often they ventured and socialised outside this. No participant said they were engaged in a relationship or had found love. The findings suggest this could have been influenced by what may have been the limited social opportunities and the negative attitude towards dating for people with learning disabilities in this period. Both Alan and Caroline discussed how they were shy and had difficulty interacting with members of the opposite sex. This could possibly be associated with the lack of exposure to the opposite sex and interaction with others outside their immediate environment.

Caroline, John, Alan and Peter all experienced living in care establishments in the 1970s. It was unclear when Peter moved from his family home and into supported accommodation but it was estimated, due to his age and family history, to be in this period. Mary, the only ethnic minority participant, was born in this period yet lived with her family until more recently. It was likely that Mary and her parents were born outside the UK, therefore her parents may have been less exposed to UK-based changes in societal attitudes towards people with learning disabilities. Participants in this period were still seen as passive recipients of care with limited autonomy regarding their

support and lives in general. Both Caroline and John gave examples in their interviews of strict rules, such as not being allowed to watch television on Sundays. Despite care services being moved to the community from hospitals, participants described living in large services in this period which suggests a lack of individualised support and lack of one to one contact. It was unclear from participants' interviews if there was a mixing of the sexes in these properties, but this appears unlikely as care services at this time were similar to the experiences of being in a hospital in terms of control and strict regimes so mixed sex service would have been unlikely. The strict protection provided by care services at this time does not suggest an environment in which love could flourish, as evidenced by the lack of relationships for participants in this period. Due to participants' descriptions of strict regimes in some care homes, it appears unlikely that they had experienced the same levels of exposure to the increasingly sexualised material portrayed within society including publications such as *The Joy of Sex* (Comfort, 1972) or *The Sun's* 'Page Three' topless models (as discussed in Section 2.2). However, staff and professionals would have experienced society's increased sexual liberation (see Section 2.2) which possibly explained why the sexual needs of people with learning disabilities began to be acknowledged and training started to be provided to both service users and their staff. This suggests that professionals had begun to consider the 'higher psychological needs' outlined in Maslow's hierarchy in relation to people with learning disabilities. However, the training was conservative in post-sexual revolution Britain, focussing solely on sex within marriage (McCarthy, 1999). It was unclear if older participants such as Alan received such training which could have influenced their desire to marry in the belief that physical affection was only acceptable in this context.

However, people with learning disabilities in this period living in institutions continued to struggle to attain the 'basic needs' of Maslow's hierarchy such as adequate food (Department of Health and Social Security, 1969). Enquiries into the three NHS learning disability hospitals highlighted that some people experienced threats to their 'safety and security needs' due to abuse and unacceptable living conditions. Opportunities to meet their 'love and belonging needs' appeared bleak as many people remained isolated in institutions, within care homes with strict regimes or 'closeted in their homes' with their sexual needs ignored (Kempton and Kahn, 1991, p.93).

### **6.2.3 1980 to 1999 - Thatcherism, Care in the Community and Emerging Presence**

In the 1980s there were still 46,000 people with a learning disability living in long-stay hospitals in the UK (Department of Health and Social Security, 1987). The white paper '*Better Services for the Mentally Handicapped*' (1971) advocated that people should receive 'care in the community' rather than in a hospital. Despite this, the first learning disability hospital closure did not take place for seventeen years. The Regional Health Board agreed to close Darenth Park Hospital in 1973 as part of the Government's policy outlined in '*Better Services for the Mentally Handicapped*' (1971), also due to poor conditions and overcrowding (Kent Parish Councils, no date). However, funding and planning for the closure took fifteen years to organise and Darenth Park Hospital did not close until 1988. This Government policy of hospital closures was a slow process, with the last learning disability hospital, Orchard Hill Hospital (Sutton), finally closing in 2008, twenty years after the first learning disability hospital closure (Brend, 2008).

In the 1980s there was significant improvement in the provision of services and support for people with learning disabilities. The first centres for supported living were established by Hampshire Centre and Derbyshire Centre for Independent Living in 1984, which demonstrated that people could learn the skills to lead more independent lives. This was a move away from being viewed as passive recipients of care. The 1984 Registered Homes Act introduced a code of practice and identified standards which residential services had to adhere to and required them to be inspected. This suggested a baseline in terms of practice and standards within care homes. However, it was possible that regulation led to more restrictions on staff and the people who lived within the properties since the homes were being observed more closely by regulators. As outlined in Section 2.2, negative stereotypes surrounding sexuality, disability and difference were being challenged in the 1980s, and this culture impacted on the development of policy and practice in relation to people with learning disabilities.

The 1990s saw the introduction of more individualised services and the concept of 'Supported Living'. Perceptions towards people with learning disabilities were changing significantly in this period and some local authorities were moving away from commissioning large registered care homes and towards supported living services (Wood and Grieg, 2010). In supported living housing, individuals were encouraged to have more independence, had a secure tenancy instead of a licence agreement and



could change support provider without moving home as housing and support were now separate. Services were financially cheaper for local authorities as it was the individual who paid for items such as rent and food directly via their benefits rather than being provided by the council (Wood and Grieg, 2010). The services typically had fewer people living there and this was significant in relation to the findings of this research as a number of participants met their partner in the house where they lived. My research suggested that, in the absence of true community integration, living in a larger care home was a facilitator to relationships. Caroline, John and Alan were all living in larger care homes when they became involved in a relationship and had they lived in a smaller service this opportunity to meet could have been lost. However, the introduction of supported living was extremely positive as it gave people more choice regarding who they lived with and more money in their pocket to spend on social activities compared to registered care where people have less disposable income (Wood and Grieg, 2010). This may have had a positive impact for people as having a higher disposable income afforded more opportunity to engage in leisure pursuits, meeting a wider range of people and, potentially, finding love.

Legislation such as the Human Rights Act 1998 and the Disability Discrimination Act 1995 made it illegal for people with learning disabilities to be discriminated against due to their disability and stated in law that people with learning disabilities had the same rights as others, including the right to relationships, to get married and a family life. The focus on integration within local communities had begun but many service providers at this stage focused on John O'Brien's (1989) 'five service accomplishments' which included 'community presence'. At the time this was radical, as people with learning disabilities had historically been isolated from society. However, people needed to have more than a mere presence in society to become active members of their communities. Owen *et al.* (2007) explored how individuals' success after leaving institutional care was dependent on a number of factors. Involvement and social opportunities not increasing was attributed to a lack of understanding and training for the staff, a dominant rule culture, previous relationships not being maintained, people not being treated as human beings and a lack of respect for their experiences. This suggests that whether individuals flourished in society or not was dependent on the quality of the staff, thus demonstrating the importance of the support provider in these situations in terms of increasing social inclusion and opportunities.

Younger participants, such as Liam, Joe and Carrie, appeared more connected within

their local community, for example, frequenting their local pub unsupported to meet friends and through their employment. A higher portion of younger people with learning disabilities in the sample went out without support and accessed more typical 'non-learning disabled' environments independently, such as local pubs. Older participants (over 35 years old) appeared less integrated, accessing their community but not to the same extent as younger participants. Older participants remained single throughout this period yet younger participants were already engaging in relationships in school with members of the opposite sex similar to peers without a learning disability in the 1990s. This suggested a significant change in attitude towards how young people with learning disabilities saw themselves, more as sexual beings with the right to engage in relationships. No younger participant had been to a residential school, as was historically typical for people with learning disabilities (French, 2010). A lack of attendance in residential schools would have led to a greater possibility of integration between sexes, as residential schools were typically segregated by sex. This increased interaction between sexes led to a possible increase in confidence in relation to members of the opposite sex.

This period provided significant opportunities for people with learning disabilities to ascend Maslow's hierarchy. The most substantial change appeared to be the closure of long stay hospitals. People who relocated to the community were typically afforded their 'safety and security needs' by having privacy, personal possessions and decent housing as a result of the Registered Homes Act 1984. Legislation was introduced to legally protect individuals' rights against unfair treatment and discrimination, including the Human Rights Act 1998 and the Disability Discrimination Act 1995. Although threats to people's 'safety and security needs' could still occur such as abuse or neglect from support staff, these threats were no longer legitimate NHS or Government practice. As discussed in Section 2.2, there was an increased focus on sex and relationships in learning disability services and training was provided to individuals and staff including increased acceptability for same sex couples (McCarthy, 1999). This highlighted how peoples' 'love and belonging needs' were increasingly acknowledged. It could be argued that it was recognised as desirable for people with learning disabilities to meet this level in Maslow's hierarchy but this remained aspirational for many, rather than attainable.

#### **6.2.4 2000 to 2009: 'New Labour', Investment in Public Services and Integration**

Although this period did not see the greatest change to policy and legislation, it witnessed the most significant changes in society's attitudes towards people with difference. There was a large increase in the number of immigrants to the UK from Eastern Europe (Park *et al.*, 2012) and asylum seekers from outside Europe (Blinder, 2011) during this period. The increase in immigration was a driver of societal and cultural change in the UK as discussed in Section 2.2. Despite the often conservative views of some immigrants in relation to sexuality (PewResearch, 2014), there were significant changes in how homosexual relationships and parenting were perceived and supported by legislation such as the Civil Partnership Act 2004 and the Human Fertilisation and Embryology Act 2008. 'New Labour' demonstrated commitment to enshrining the rights of marginalised groups in law, and this outlook was extended to people with learning disabilities.

In the 1960s and 1970s, there was a drive to improve services and opportunities for people with learning disabilities. Examples of this included the Chronically Sick and Disabled Persons Act 1970 and the publication of '*Better Services for the Mentally Handicapped*' (1971) (see Table 9). In the 1980s and 1990s there was a drive for people with learning disabilities to be heard by society/policy makers and legislation was introduced to ensure they received certain standards of care and support, including the Registered Homes Act 1984 (see Table 9). The period 2000- 2009 focused on ensuring equality and putting people with learning disabilities in control of their lives with real opportunities, providing people with learning disabilities with the same opportunities as the mainstream population such as paid employment, active involvement in their communities, relationships, the freedom to choose their support and to own their own home. Examples included *Valuing People* (2001) and *Valuing People Now* (2009) (see Table 9). The Mental Capacity Act 2005 enshrined in law people's right to make decisions (even if unwise) if they had the capacity to do so. People were defined as having capacity (whether they had a learning disability or not) unless proved otherwise. This not only encouraged people to make their own choices but made it illegal to stop them from doing so if they had the capacity to decide.

The publication of *Valuing People* (2001) was significant as it set out how the Government would provide new opportunities for adults with learning disabilities to live full and independent lives as part of their local communities. It was ambitious, driven by

four key principles: rights, independence, choice and social inclusion (Fyson, 2009) and focused on improving key areas such as housing, support, employment and community integration. *Valuing People* (2001) outlined that people with learning disabilities should have equal access to employment, be able to enjoy sexual relationships, get married and live as independently as possible. *Valuing People Now* (2009) identified that *Valuing People* (2001) had not achieved all that it intended and there was still some way to go for people with learning disabilities achieving the same rights and opportunities as other citizens. *Our Health, Our Care, Our Say* (2008) outlined the introduction of personal budgets which aimed to give people maximum control through paying their own support staff but, in reality, this did not have the impact intended. In 2008 a survey showed that 37% of social workers were concerned about the Government agenda to ensure all people had a personalised budget by April 2013, compared to 38% who believed this was the right direction for social care. Social workers feared that personal budgets were not suitable for everyone, either because they lacked the ability to manage their own budgets or were vulnerable to safeguarding issues (Mickel, 2008). Mary had experienced financial abuse and required safeguarding.

Duffy (2006) claimed that the introduction of personal budgets would give people with learning disabilities more control over their lives, and allow them to more effectively use their own social support networks such as friends and neighbours, therefore reducing the need for paid support. Fyson (2009) argued that there was financial pressure to reduce the cost of social care and that attempts were made to present decreases in service provision as a way of increasing independence rather than as budget cuts. Fyson (2009) highlighted how this approach could leave individuals more vulnerable to abuse: for example, it would be harder for a person to raise a safeguarding concern if the alleged abuser was from within their own social circle. Personal budgets often result in a reduction of support hours which could increase loneliness and make people more vulnerable to 'befriending' by abusers (Fyson, 2009). However, the uptake of personal budgets within local authorities was lower than expected and only 23,610 adults with learning disabilities had a direct payment and/or personal budget in 2009 (*Emerson et. al.*, 2010).

Younger participants in my research (under thirty five years old) grew up within this period (2000- 2009) and had limited experience of the old institutional practices and attitudes. Expectations to have their own home, jobs and a partner who loved and

supported them appeared higher among younger participants. The development of more progressive attitudes within society towards people with learning disabilities appeared to have changed the way in which young people with learning disabilities view themselves. In contrast to the older participants, the younger participants appeared to view themselves rightfully as equal and deserving of 'normal' experiences such as finding love, marriage, a fulfilling physical relationship and the opportunity to live alone with their partner. Liam, Dean, Emma, Carrie and Joe all defined themselves as 'in love' and were either married or engaged and wanted to live alone with their partner.

All of the participants began their relationships between 2000 and 2009. This was a notable finding as it suggests that relationships were probably not encouraged until the changes in societal attitude and legislation that arose post-2000. According to the findings this appeared to have led to an increase in the number of people with learning disabilities who found love, compared to none of the older participants having experienced love prior to this date except for John (although he did not define it as 'serious;'). *Valuing People* (2001) led to an increased focus on the individual as part of a 'circle of support' and the importance of non-paid relationships for people with learning disabilities. This could have shifted staff practice towards an increased focus on the development of relationships for the people they worked with, instead of discouraging them as they historically had been.

Perhaps the changes in thinking which occurred in this period may have come too late in the lives of older participants. This possibly resulted in older participants having lower expectations of relationships than younger participants, for example, in their expectations of having a fulfilling physical relationship (even if this was not sexual) or the opportunity to live separately from others as a couple. This may have been due to some older participants (Peter, Mary and Alan) having higher support needs compared to younger participants, and combined with their age, perhaps inhibited staff and other influences from encouraging them to have similar expectations as younger participants.

The most influential development within this period appeared to be a change in perception to people with learning disabilities. In relation to Maslow's hierarchy, it could be argued that there was now a belief in society that people with learning disabilities should be supported to attain all of the levels instead of just the earlier ones. This was evidenced in publications such as *Valuing People* (DoH, 2001) which could be

interpreted as encouraging people with learning disabilities to strive to attain the 'higher psychological needs' of the hierarchy such as 'love and belonging needs' by having relationships and 'self-esteem needs' via employment. *Valuing People Now* (DoH, 2009) highlighted, however, that fewer people with learning disabilities were in socially valued roles than was hoped, but at least such an idea was no longer considered aspirational and were beginning to be expected by regulators (such as CQC), commissioners and people with learning disabilities themselves.

### **6.2.5 2009 to 2013: Austerity, Global Recession, Spending Review, Cuts to Social Care and Winterbourne View**

The most significant external change to social care change that took place within this period was the global recession. A global recession was defined by the International Monetary Fund (IMF) as 'two consecutive quarters of decline in a country's real (inflation adjusted) gross domestic product (GDP) - the value of all goods and services a country produces' (IMF, 2012). The recession affected the UK by increasing unemployment, reducing property sales and values, decreasing migration to and from the UK and a reduction in gross earnings (Office for National Statistics, 2011). Due to the recession, the Government retrenched and this led to a reduction in social care spending. All local authorities continue to face increasing pressure to cut costs and the most vulnerable people continue to face the brunt of the cuts. '£23.7 billion of annual cuts will fall on disabled and older people and people living in poverty – 58% of all cuts' (Campaign for a Fair Society, 2012, p.1). As support services become increasingly stretched financially it is likely that this will influence social support and individuals could become increasingly socially isolated making it even more difficult for them to find a partner and form a loving relationship. A reduction in social support can also affect the ability to maintain existing relationships, such as going on dates, in cases where individuals are unable to access their community independently. Due to the embodied reality of their learning disability, Mary and Peter have relied on staff to support them in travelling independently and with other practical support such as paying for items. Others require physical assistance, like Alan and his wife who is physically disabled, and he requires help with pushing her wheelchair.

Cuts to social care will undoubtedly pose further challenges to improving the lives of people with learning disabilities. Despite the advances in public attitudes and legislation, this marginalised group continues to face challenges to their human rights

including suffering abuse and institutionalisation. The BBC Panorama programme aired in May 2011, uncovered the abuse experienced by residents at Winterbourne View, a private hospital for people with learning disabilities in South Gloucestershire. The programme highlighted how, despite all the advances in social care in the previous four decades that has been outlined, large numbers of people with learning disabilities continue to live in private hospitals. This is a significant regression in the provision of social care provided for people with learning disabilities. The fact that such a large number of people remained incarcerated within these environments was a shock to the public and social care professionals. People at Winterbourne View lived in an 'assessment and treatment service' with 24 patients living on two wards and the *Serious Case Review* (Flynn, 2012) identified that conditions there were like those within older institutions, for example, patients were restricted from meeting with visitors in any private location other than the communal lounge. Staff were poorly trained and supervised and there was little interaction with outside agencies (Flynn, 2012). The NHS hospitals had been replaced by private funded hospitals and those who lived there still experienced the levels of social isolation and institutionalisation other people with learning disabilities had experienced twenty years before. An investigation by *Community Care* (2013) found that people remained in these environments for 23 months on average, but 18% of the people had been there for five years or more and 3% ten years or more. This was at least a reduction from the 31% of people who had remained there for five years or more in 2010 (Pitt, 2013).

The Association for Supported Living (ASL) which represents over 75,000 thousand people with learning disabilities produced a report '*There is an Alternative*' (ASL, 2011) which highlighted how a service such as Winterbourne View costs more than their suggested alternatives but has poorer outcomes for the service users. Because of this scandal, CQC inspected 150 hospitals and care homes and, while it did not find abuse on the scale of Winterbourne View, it identified that people were being placed in these private hospitals unnecessarily and often remained there indefinitely. The report advocated that those who did not require hospital care should be moved back into the community by June 2014. Opportunities for people to have an 'ordinary' relationship, which includes having the privacy to live alone together as a couple, and to go out for dates/shared activities were impossible while people remained in such environments. Thus, the participants in my research are possibly some of the luckier ones.

Cuts to public spending have affected the care sector in other ways, such as the level

of staff pay. Wages are paid predominantly by local authorities who have to reduce costs, resulting in lower wages for staff. Prior to the recession the Commission for Social Care Inspection (CSCI) identified that there were 'chronic difficulties' in the recruitment and retention of social care workers (Commission for Social Care Inspection, 2005). Pay has been historically low in social care services, generally little above the minimum wage (Hussein, 2010) and low pay, combined with the poor social status associated with the roles available, has significantly impacted on recruitment and retention of staff (Low Pay Commission, 2010). The low wages and status in much of the sector has been unappealing to UK workers, resulting in an increase of workers from outside the UK and Europe (Hussein, 2010). A report from Patmore (2003) identified that two independent agencies in London reported that 80% of their staff was from ethnic minorities, largely Afro-Caribbean and African. This was representative of the staff encountered during my interviews within the London-based organisation.

Research has demonstrated that in some developing countries such as those within Africa, meeting the basic human rights for people with disabilities is challenging (Anderson, 2003). It is unclear what impact growing up in a developing nation has on staff values towards people with learning disabilities and how their values influenced practice. Non-UK workers have not grown up being influenced by the attitudes and legislation outlined in Table 9. For example, a survey was conducted to identify how important religion was considered in peoples' lives: within the UK only 26.5% considered it important compared to Nigeria (100%), Bangladesh (100%), Oman (99.5%), Indonesia (99.5%) and Somalia (98.5%) (Gallup, 2009). Almost all of the countries within the top ten were African or Asian. European countries featured significantly lower. Many individuals are drawn from such communities to work within social care. It is unclear how the religion of the migrant workers from African countries influences their judgement regarding the acceptability of some behaviours but Section 2.2 highlighted how they can hold views that are not tolerated by the majority of people within the UK such as prejudice toward homosexual relationships or sex before marriage (AVERT, no date, PewResearch, 2014). No research was identified to determine the impact on support in terms of relationships, however, it could be hypothesised that staff who hold strong religious beliefs might be less encouraging if the relationship involved a sexual element.

As recently as 2013, some people with learning disabilities still resided in private isolated institutions such as Winterbourne View. This indicated that limited lessons



were learnt from previous abuse scandals. People with learning disabilities continue to experience threats to their 'safety and security needs' which originate from those in a position of power such as staff who were entrusted to protect them. This period highlighted how that despite the advances made in both policy and practice as outlined in Table 9, people with learning disabilities still experience significant threats to their 'safety and security needs' which impact on their ability to ascend Maslow's hierarchy.

### **6.3 Summary of Key Developments in Policy, Practice and Attitudes**

In summary, there have been many changes in attitudes towards people with learning disabilities over the course of the participants' lifetimes and this has been reflected in the legislation and events that evolved as a result. There was evidence to show how far people with learning disabilities have progressed within society; pre-1960 people were incarcerated in institutions sometimes unable to reach even the most 'basic needs' of Maslow's hierarchy such as adequate food. Public perception was they were 'useless or dangerous' individuals requiring constant assistance (Brown, 1994) to individuals capable of work and with the same rights as adults without learning disabilities (DoH, 2009). However, this Section also reminds us what challenges this group have faced in attaining the levels outlined in Maslow's hierarchy and their on-going struggle for respect and equality from society.

My research identified that participants valued having a partner to love and who loved them, however this Chapter identified the historic barriers people have faced which possibly stopped them from finding love and making a secure attachment. People with learning disabilities continue to face discrimination, are less likely to be employed, married or living with a partner and have a family. They frequently live in care homes or supported accommodation and some remain segregated from mainstream society. What has changed is that now people with learning disabilities have the same legal rights and responsibilities as the wider population, as enshrined in laws such as the Human Rights Act 1998 and the Equality Act 2010. Such rights include the right to family life, to have the same access to leisure and community resources, the right to have friends and family contact and the right to be protected from abuse and discrimination. Since the 1990s there has been a clear drive to include people with learning disabilities in policy development, to increase their standing within society and to increase their autonomy in terms of service provision. This could be interpreted as

an active attempt by society to increase the 'self-esteem needs' of people with learning disabilities by declaring they should aspire or be supported to meet the levels outlined in Maslow's hierarchy and attain socially valued roles such as employee, spouse/partner or parent. The aspirations outlined in *Valuing People* (2001) or *Valuing People Now* (2009) may not have been fully met, but it is now clearer to what most organisations should be aspiring.

Sadly, the case of Winterbourne View and the case of 'Lisa' (CQC, 2014) demonstrate that this is still not practised by all. A significant threat now to improving the lives of people with learning disabilities appears closely tied to economics. The global recession, combined with the increasing cost of social care due to an ageing population, has significantly impacted on social care funding. It is unclear at this stage how this will affect individuals' abilities to form and maintain relationships but it is unlikely to be positive. The forming and maintaining of loving attachments has been considered fundamental to human existence (Bowlby, 1979 and Ainsworth *et al.*, 1978). If people with learning disabilities lack autonomy, they are more vulnerable to isolation. The lessons learnt from cases such as Winterbourne View (Flynn, 2012) demonstrate that limited relationships increase vulnerability and therefore can threaten 'safety and security needs'. It could be argued that relationships, either with a partner, family or friends, provide an additional layer of protection in regards to meeting and retaining 'safety and security needs'.

Chapter 7 will reflect on the themes identified in the previous three Chapters in terms of the wider literature which was discussed in Chapter 2.

## Chapter 7- Discussion

### 7.1 Introduction

The previous Chapter considered how key developments within the history of people with learning disabilities, such as changes in legislation, policy and societal attitude, have shaped the lives of participants. This Chapter builds upon this, exploring how the findings compare to the relevant literature. Most of the literature was presented in Chapter 2, but some new literature which is considered relevant in light of the findings that arose in the research will also be included. Although this study is unique in its aims, the findings can be discussed in relation to the wider literature. The small number of participants in this study inevitably means that generalisations should not be made, rather, this Chapter seeks to comment on whether the findings in this study support, contradict, or add to the available literature.

The research questions were 'what do people with learning disabilities look for in a potential partner and how do their prior experiences affect their choices and influence the relationships they experience'. Two theoretical approaches, attachment theory and Maslow's theory of human motivation, were identified as being significant in regards to the relationships and partner selection for people with learning disabilities. The findings will be discussed in relation to both approaches. In answering the research questions, my hermeneutic phenomenological analysis identified four themes (discussed in Chapter 5) which included: partner selection, sexual and physical relationships, the influence of staff/ group living, and societal and familial influences on relationships. The interaction between the four themes and corresponding sub-themes raised two key questions (discussed in Chapter 5) which were:

- What brings people with a learning disability together and holds them together?
- What stops people with a learning disability getting together or staying together?

This Chapter explores these two questions and the primary research question within the context of the relevant literature and the theoretical framework delineated in Chapter 2. This raises the three areas for discussion which will form the basis of this Chapter: finding love as an adult with a learning disability; attracting and attaching; maintaining a relationship as an adult with a learning disability.

Chapter 7 will examine the barriers and facilitators to relationship for people with learning disabilities, including finding love as an adult with a learning disability; attracting and attaching; and maintaining a relationship as an adult with a learning disability.

## **7.2 What brings people together: Finding love as an adult with a learning disability**

This Section will consider the factors that influence how my participants, people with learning disabilities, select a potential partner and make secure loving attachments. The factors included: social circle, housing and social exclusion. Some factors were unique to being an adult with a learning disability while others replicated issues identified within the general population which was identified by the research literature.

### **7.2.1 Social Circle**

My findings confirmed that adults with learning disabilities desired a sense of love and belonging comparable to their peers without learning disabilities as identified in the literature outlined in Section 2.3. This was a 'basic need' and was unaffected by age or IQ. One of the most significant findings within the research was that participants valued the companionship that a partner provided over many other aspects of the relationship. As claimed by attachment theory (Bowlby, 1978), the strong desire to bond with a committed partner is central to maintaining a relationship. This was identified throughout the literature for people without learning disabilities as a main driver to the formation of relationship (Rubin, 1970, Berscheid and Walster, 1978 and Sternberg, 1996). My findings also reflected the findings of Craft and Craft (1979), where marriage was identified as a way to reduce loneliness, especially for people with learning disabilities who came from 'unhappy families' or grew up in institutions, a number of participants in my research had been 'let down' by others (see Chapter 4), making it even more understandable that they valued a bond with a committed partner. Hazan and Shaver (1987) identified that poor attachments in childhood are more likely to lead to poor relationships with a partner in adulthood. This did not appear to have been replicated in my research, as all of the participants experienced loving relationships, despite some of them having possibly experienced poor attachments in childhood. Mattinson and Sinclair (1979) identified how some individuals settle for poor-quality or abusive relationships to alleviate loneliness. Reflecting on the findings, it was positive that no participant settled for a damaging relationship, as this can be an issue for some

women with learning disabilities (McCarthy, 1999). Kerry was able to stand up to an abusive ex-partner and terminate a relationship and Emma was able to do the same with staff support. However, there may have been an element of settling for John as his abusive relationship only ended as his former partner moved home. Hodges and Tizard's (1989) argued that children, like John, who spent a period in institutional care had poor attachments in childhood and adulthood. John was now in a loving relationship with Caroline, suggesting it was possible to overcome such issues with the love of a good partner later in life.

Factors such as a small social circle and isolation can impact on the ability of a person with a learning disability to find a partner and make a loving attachment. Craft and Craft (1979) and Mattinson (1970) identified how social isolation for people with learning disabilities was an issue over forty years ago and this can still be the case. Social inclusion was a key objective of *Valuing People* (DoH, 2001), yet Emerson and Hatton (2008) maintained that people with learning disabilities had less contact with friends compared to the wider population. Key stakeholders such as support providers, social workers and policy makers could consider the lack of full integration of people with learning disabilities into society as being a failure. Attachment theory stated that the forming of loving relationships was a 'basic need' (Ainsworth *et al.*, 1978). Finding a potential partner requires interaction with others but if this is not happening, it limits individuals' opportunities to find love. Maslow's theory made limited reference to the importance of friendships, but an inadequate social circle could limit an individual's ability to meet their 'love and belonging needs'. Emerson *et al.*'s (2005) survey concluded that younger people were more likely to have contact with their family and friends. My findings also found that younger participants typically had a wider social circle. Both Carrie and Joe and Liam and Emma confirmed they had sufficient friends whom they saw on a regular basis and had more contact with the family than older participants. Kerry was the exception to this: she had few friends and limited family contact and had grown up in care, whereas other younger participants had lived as part of the family unit until they reached adulthood. This suggested a possible link between growing up in a family home and wider social circles in adulthood.

Emerson and McVilly (2003) argued that people with learning disabilities who lived in supported accommodation had low levels of friendship related activities. A lack of friends and small social circles was identified by various participants in supported accommodation. Caroline, John and Peter all appeared to have small social circles. It

was unclear if Alan had a small social circle yet his strong desire to 'meet people' suggested it was not as wide as he would have liked. My findings, however, did not suggest that this was due to the participant's accommodation but appeared related to age. Mary was the only older participant who felt that she had sufficient friends, but she did receive a high level of support from staff which could have eliminated any potential feelings of loneliness. McVilly *et al.*'s (2006) research confirmed that participants found it harder to make friends once they left school. Younger participants in my research went to school locally and therefore had possibly retained contacts while some older participants appeared to have moved outside their local area. This suggested the importance of maintaining community links to retain friendships and the focus on supporting older adults to build and maintain social networks. Sufficient social circles could increase people's opportunities to find love and this could be achieved via real community integration and prominence afforded to the development and maintenance of friendships by support staff.

Being older did not stop participants from finding love, but the lack of opportunities experienced by older participants (as discussed in Chapter 6) may have limited their ability to meet a wider range of potential partners. It was possible they may have found a partner with whom they were more compatible. For example, if Caroline had a wider social circle she may have met a partner who wanted to marry her. It was possible that the social care providers had not been sufficiently pro-active in encouraging new relationships and friendships for some individuals, therefore not meeting their 'love and belonging needs'. However, staff stated that Peter had resisted this support when offered, preferring to spend time with his wife.

An alternative explanation for why people had small social circles can be offered which is unrelated to their environment and focusses on internal barriers to forming relationships. Simpson and Rholes (1994) and Collins and Reed (1990) argued that individuals who lacked a secure attachment in childhood were less trusting and more cautious in developing relationships. As identified in Chapter 4, Peter, Caroline, John and Kerry had possible attachment issues. They all had few friends as adults and it was possible that their early experiences affected their ability to form friendships due to a lack of trust and fear of rejection. However, unlike the findings of Hazan and Shaver (1987), participants were able to form a loving attachment with a partner despite possible attachment issues. An interpretation could be that the relationship they experienced with their partner was different, perhaps higher in elements such as

acceptance, warmth, affection or trust, which possibly assisted participants to overcome these issues (to some extent), but this was not always extended to developing friendships where people remained cautious due to their previous experiences.

### **7.2.2 Housing**

Kerry was the only younger participant to appear socially isolated. In terms of Maslow's theory her 'love and belonging needs' were unmet as she had no close friendships and poor relationships with family. This displayed parallels with the findings in Emerson *et al.* (2005), which found that people living in support services had more contact with friends than those living in the family home who tended to be more isolated. Although Kerry did not live in the family home she was the only participant to live alone in a flat and not as part of a shared block/house (except for Dean and it was not possible to determine if he was socially isolated due to limited contact). These findings suggested that living alone did not allow the same social opportunities as living in a group environment. Moving into an independent flat was an achievement but there is a risk that people can become more socially isolated if they do not have a sufficient social circle to engage with. People who gain independence and, therefore, require less support can suffer from isolation and become more vulnerable to exploitation (Simpson and Price, 2010). This highlights the need for support providers to monitor individuals who move into their own accommodation and ensure support is provided around developing social networks so individuals are less isolated. It was unclear what support Kerry had received in this area. The challenge for social care providers would be balancing how to monitor the individual (which suggests a paternalistic attitude) while enabling them to have their freedom and autonomy.

Caroline and John said they felt lonely despite living in a larger care home. This was most likely due to the people they were sharing with having much higher needs than theirs' and making it less likely that they would have engaged meaningfully with their housemates. As it was a care home as opposed to a supported living service they had not chosen who they lived with. People could feel socially isolated if their support needs were significantly lower or higher than those they share accommodation with and this should be a fact considered more carefully by commissioners when assessing referrals to properties. It is recommended that improvements to the system should be considered to ensure that individuals have broader options when selecting where to

live and who to live with. In principle, couples such as Liam and Emma should be able to live alone as a couple if they desire and individuals should have the opportunity to not share their home with someone. This is, however, related to other factors. For example, the ability to live alone as a couple without constant staff support is dependent on the support needs of the couple, it is also dependent on what funding is available to them and if suitable housing is available. Affording couples more choice to live alone would assist in avoiding the issues highlighted by Liam and Emma's interview where staff are required to mediate tension between the different needs and rights of those living within communal homes. Both Liam and Joe discussed how they visited their current house to decide if they wanted to live there, however it was unknown what other options were available to them, including the opportunity to live alone, and whether that would have been a realistic option. *Valuing People Now* (2009) identified that people with learning disabilities should have the right to choose where they live and who they lived with. However, in 2009 just 15% of adults with learning disabilities rented their own home (compared to 70% of adults without a learning disability), 50-55% still lived within the family home and 15% lived in care homes. Seven participants in this research rented their own home, four people lived in a care home and no person lived with a family. The participants who lived in care homes appeared most unhappy with their accommodation or had less in common with those they lived with. The apparent lack of choice afforded to participants implied that in terms of Maslow's hierarchy, the participants with learning disabilities were still not being seen as sufficiently autonomous to have their right to live where and with whom they desired recognised, thus not fulfilling their 'self-esteem needs'. Tensions between housemates relating to privacy, which was required to have intimate conversations, could impact on individuals' ability to form loving attachments (Hollomotz, 2008). Support providers need to be proactive in challenging placing authorities if vacancies are not being filled based on the tenants' requirements and compatibility and to offer a broader choice of where and with whom to live.

Lesseliers (1999) researched the impact of participants' living situations on their ability to develop relationships and suggested that living in a group environment made it 'practically impossible to have a normal relationship' (p.140). My research contradicted this claim as four couples met their partner at their home and it was here that love blossomed, as it did with the majority of participants in research by White and Barnitt (2000). My findings were more positive than Lesseliers' (1999) and mirrored White and Barnitt (2000) in that staff actively supported or accepted the relationships. Meeting a



partner in a shared house may not be ideal, but the reality is, that despite advances in the community integration of people with learning disabilities into wider society, there are still stark differences in terms of access to accommodation, employment and leisure activities for people with learning disabilities compared to non-disabled adults. Environments such as shared accommodation remain a common place to meet partners for people with learning disabilities. If people had the opportunity to live alone (such as Kerry) it could contribute to increasing their 'self-esteem needs' by being able to live independently, however if their social circles are limited as outlined in Section 7.2.1, people may not have the opportunity to meet a potential partner and form a loving attachment and meet their 'love and belonging needs'.

Arguably, some participants may have selected a partner due to their availability, possibly over key factors that influence partner selection for people without a learning disability, such as shared life goals, values and common interests as identified by the typology in Appendix 1. No participant acknowledged this in interviews but it was alluded to by Caroline and John, who did not share the same views on topics such as physical contact, marriage and were unable to live together, yet remained together as a couple. In addition, Mary claimed to 'like Gary most' as he was available to her more frequently than her family. The type of environment people lived in was possibly irrelevant in terms of finding a partner: the most important factor appeared to be the scope of their social circle. If this was small people could settle for who was available (possibly in their home) rather than finding someone who was more compatible. This appeared reflective of Lee's (1973) love style Pragma, a practical type of love where individuals were realistic about the partner they selected based on circumstances and availability. This implied support for attachment theory's view of love as a 'basic need', having someone to love was so important that differences were overlooked. This was possibly due to the reparative nature of having a loving partner considering the abuse, rejection and abandonment some participants had experienced.

### **7.2.3 Social Exclusion**

*Valuing People Now* (DoH, 2009) identified that almost a decade after *Valuing People* (DoH, 2001) people with learning disabilities still had fewer relationships than their non-disabled peers, which they concluded was due to their exclusion from places where people would typically meet potential partners, such as at work and clubs. Emerson *et al's.* (2005) survey demonstrated that 75% of people with learning disabilities only had

friends with a learning disability. People were more likely to have friends without a learning disability if they were younger, had lower support needs and were employed. McVilly *et al.* (2006) identified the stigma some people with learning disabilities experienced from adults without learning disabilities, describing how they had been openly rejected as a friend and feared integration was not realistically possible. McVilly *et al.* (2006) concluded people with a learning disability felt more comfortable being friends with people with learning disabilities, believing that 'sharing the experience and identity of intellectual disability appeared to enhance the sense of equality' (p.703). This may also be applicable to their relationships.

All of the participants were in relationships with other people with a learning disability and the greater equality between them as a result may have been a facilitator of the relationship. The fear of rejection due to their disability, as identified by McVilly *et al.* (2006), may have led participants to exclude the possibility of potential partners without a learning disability. There is no research depicting the number of relationships between those with a learning disability and those without. However, in my experience, such relationships raise safeguarding issues with social workers, such as the legal case of SK (2008) (see Chapter 2 for more discussion). Within Craft and Craft's (1979) research 24% of couples included one partner without a learning disability, although none was described as 'bright' and often had other issues such as mental health issues/criminal behaviour. This implies that the caution towards this type of relationship has only existed in recent years, possibly due to the increased awareness of safeguarding issues.

Social stigma was not explicitly stated by the participants but Carrie and Joe were the only participants who claimed they had friends who did not have a learning disability (they met these friends through their employment). Carrie and Joe were also in the minority in that they had paid regular work outside of the learning disability environment. This confirmed that access to employment can widen individuals' social circles and create more opportunities for engagement with those who do not have a learning disability and thereby increasing integration. McVilly *et al.* (2005) agreed, claiming people with learning disabilities who were employed were less likely to be lonely. The lack of friendships between people with learning disabilities and people who do not have a learning disability, in combination with the implied stigma people continue to face, suggests that society has a long way to go to fully include and value people with learning disabilities. It could be argued that people were not having their

'self-esteem needs' met as they were excluded from society, experienced stigma and were not visible in socially valued roles via employment. More people with learning disabilities finding employment may contribute to addressing these issues and change society's attitude.

It could be argued that changes to our culture and the introduction of a welfare support system have increased exclusion for people with learning disabilities'. Prior to the industrial revolution people with a milder learning disability (like those individuals included in the research) would have been able to play more of an equal role in community life (Jamison, 1998). Significantly fewer people were educated with only two universities existing in England (Oxford and Cambridge) in 1800, with very few people attending them and all who did were male (National Archives, no date). Most jobs were manual and agricultural in nature (National Archives, no date) and did not require higher levels of education so it's possible that people with milder learning disabilities pre the industrial revolution would have had the same level of social opportunities and access to the employment that was available. It was the advancement in technology, the development of industry and the requirement for skilled labour after this time which made it more difficult for people with learning disabilities to contribute to society from this period onwards, which was less of the case in agricultural, pre-industrial Britain (Race, 1995).

Bates and Davis (2004) highlighted how advocates of social inclusion have 'rightly highlighted the importance of waged employment as a route to income, status and relationships' (p. 198). *Valuing Employment Now* (2009) identified that 65% of people with learning disabilities expressed a desire to be employed. However, Emerson *et al.* (2012) reported that in 2011/12 only 7.1% of people with learning disabilities in the UK were in paid employment. Of the 7.1%, 89% worked part time (less than 30 hours per week), although voluntary rates of employment had risen to 6.2% from 5.5% the previous year. Despite the recession there was a small rise in the number of people in paid employment in the previous two years from 6.6% to 7.1%. This remains a significantly lower percentage compared to countries like the USA where the number of people with learning disabilities in paid employment in 2010 was 26% (Butterworth *et al.*, 2011).

*Valuing Employment Now* (2009) identified that the benefits system at present does not always incentivise people to work and that people benefit most financially when they

work over 16 hours a week. This often leads to a fear among both support staff and the people themselves that they will 'lose their benefits'. This fear implies a lack of belief in adults with a learning disability that they will be able to maintain the job and no longer require benefits. *Valuing Employment Now* (2009) identified that there needed to be a large shift in attitudes overall to increase employment for people with learning disabilities. There was evidence to demonstrate that there was little incentive to work for some individuals with just 17% of people in paid work earning over £100 per week (Emerson and Hatton, 2008), making them financially better off to remain in receipt of benefits. *Valuing Employment Now* (2009), published prior to the Comprehensive Spending Review (2010), was abandoned by the Government in 2011 and has not been replaced by a new initiative. Post-2010, there have been significant cuts to social care hours which may have negatively impacted on individuals' access to employment. Support services have been reduced and non-essential services have suffered heavily. Although there were no statistics available to support this it is likely that people will not get the support to search for jobs search or support to do the job if this is required. The DWP provides funds to councils for employment support, but as a result of the cuts to social care, there is a fear this will be reduced as it is deemed non-essential and councils have to make 25% cuts in the period 2011-15 (Samuel, 2010).

Supporting people with learning disabilities into paid employment needs to be a higher priority on society's agenda. The Government needs to make a commitment to increasing the number of people with learning disabilities in paid work, either via a renewed commitment to *Valuing Employment Now* (2009) or another similar initiative and provide the finances to fund it. This may be difficult in the current economic climate. However, a review of the expenditure for such an initiative may demonstrate that the reduction in costs of benefit payments from getting people into work may outweigh the costs of funding such an initiative. The increased presence of individuals with learning disabilities in mainstream locations such as the workplace will assist in reducing the stigma of having a learning disability and promote integration. Waged employment for people will increase their social status, encourage inclusion, reduce loneliness and increase opportunities for making friends and finding love. Despite the advances in the lives of people with learning disabilities, many remain rooted in the lower levels of Maslow's (1943) 'Hierarchy of Needs'. Their 'basic needs' such as food and security have been met, but they frequently failed to attain higher levels such as 'self-esteem needs' which include self-respect, respect from others and a sense of achievement. This will not be reached until people with learning disabilities are viewed

and treated as equals in society with the same rights and opportunities as people without learning disabilities.

## **7.3 Attracting and Attaching**

Section 7.2 presented the factors that can influence how people with learning disabilities select a potential partner and find love. This Section will consider how people attract and attach to a partner. The literature review did not identify any research that examined what people with learning disabilities desire in a potential partner which my research now addresses. This Section explores the possible reasons behind their choices, examining how a shared history and culture may influence what people value in a potential partner. In some instances the participants expressed their love differently to the descriptions found within the literature for non-disabled peers outlined in Section 2.3.4 by rejecting traditionally valued characteristics/traits/factors such as intelligence, dependability, physical attractiveness and a lack of focus on a sexual relationship. This 'shared rejection' possibly acted as a facilitator in bringing and keeping the couples in this research together.

### **7.3.1 Intelligence**

One of the main differences between participants and those included in the typology (see Appendix 1) was the value attributed to intelligence, especially by females. For participants without a learning disability this was a valued trait (Regan, 1998, Regan and Anupama, 2003 and O'Reilly *et al.*, 2009) The consensus within research for people without learning disabilities is that intelligence is important because it often leads to better employment opportunities and higher social status. No participant in my research claimed to value intelligence in a potential partner and participants stated that a partner's employment status was irrelevant. People with learning disabilities appeared not to share identical cultural norms as the wider population but this was understandable considering how their experiences often differed from their peers without a learning disability (see Section 2.2 and Chapter 6). For the participants with learning disabilities better employment opportunities and higher social status appeared to be less relevant, unsurprisingly, as in 2012 only 7.1% of people with learning disabilities were in paid employment in the UK and the majority were in receipt of benefits (as was the case with my participants) compared to the general population where 67% (males) and 57% (females) were employed (Emerson *et al.*, 2012). The

economic and social situation for people with learning disabilities is often not ideal, but a positive interpretation could be that as a result people with learning disabilities have the opportunity for a less restricted expression of love. People with learning disabilities, unlike their non-disabled peers, may have less need to share in the socio-economic pressures of having a partner who fulfils criteria that could enhance employment opportunities and social status (Levesque and Caron, 2004), possibly affording them a wider range of potential partners. This provided further support to attachment theory's view of love in relationships as a 'basic need' as opposed to Maslow's description as a 'higher psychological need'. People with learning disabilities in this research did not appear to consider relationships as a way of increasing financial security or social status as traditionally defined in Appendix 1 although they possibly considered relationships as means to reduce social stigma.

Intelligence has not always been explicitly defined in studies relating to partner selection (Regan and Anupama, 2003 and O'Reilly *et al.*, 2009). 'Intelligence' is a controversial term with varying definitions that typically include references to cognitive functioning, conceptual thought, problem solving and abstract reasoning (Binet and Simon, 1914; Wechsler, 1944 and Sternberg, 2000) and on the basis of traditional definitions of intelligence people with learning disabilities would not be considered intelligent. Currently, those defined as 'having a learning disability' have an IQ under 70 (Department for Work and Pensions, 2008). Gardner (1983) identified that traditional IQ testing does not explain all cognitive abilities and proposed there are multiple forms of intelligence. Gardner (1983) identified forms of emotional intelligence such as 'interpersonal and intrapersonal intelligence', which was the ability to understand the behaviours of others and the capacity to self-reflect and understand one's own feelings and behaviour.

Some participants such as Liam, Emma, John, Caroline, Carrie and Joe displayed high levels of emotional intelligence, evidenced by being able to interpret the behaviour of others, especially their partner, and provide the correct emotional support. For example, Emma was able to negotiate conflict between Liam and staff following an argument and Joe was able to provide emotional support to Carrie in relation to an attempted sexual assault. Dunn *et al.* (1991) emphasised that parental relationships characterised by discussing emotions/feelings and high levels of self-disclosure resulted in adults who were more sophisticated in their understanding of others. Liam, Emma, Caroline, Carrie and Joe all grew up in a family environment and all described a

loving relationship with at least one parent. This possibly provided an opportunity for them to have had such a relationship with a parent which enabled emotional intelligence to develop. The participants who had experienced this form of support from their partners valued it highly. This implies that while participants may not value intelligence as it is traditionally defined (IQ) they may value different aspects of intelligence more. This was also reflected by the different definitions of intimacy defined by Holt et al. (2009) in Section 2.3.3; Emma's ability to negotiate conflict demonstrated intellectual intimacy and Joe's ability to support Carrie demonstrated emotional intimacy. The ability to express a level of emotional intelligence and differing types of intimacy may increase the likelihood of participants forming a loving attachment. This suggests that in relation to Maslow's theory, individuals who could express intimacy were more likely to be able to meet their partners 'love and belonging needs'. This aspect of their partner's personality contributed to the feeling of being 'loved' and played a role in keeping couples together.

Table 3 (in Section 2.5) presented the defining essential characteristics of an exclusive relationship as compiled from the main theories identified within the literature search. On reflection, all of the participants, regardless of intelligence, were compassionate, tender and affectionate towards their partners and such traits have been defined as key components of 'love' (Berscheid and Walster, 1978 and Graham, 2011) and Maslow's (1954) B-love. All of the participants remained exclusive and committed within their relationship, which has also been representative of 'love' for adults without a learning disability according to the literature in Section 2.3 (Rubin, 1970). Participants valued traits highlighted by adults without learning disabilities in the typology (see Appendix 1), including kindness and consideration, which were comparable to Graham's (2011) 'compassion'. They also valued an emotional bond with a partner, which was comparable to Rubin's (1970) 'intimacy' and Sternberg's definition of 'commitment' (1996). There was also evidence that the participants in my research represented at least two of Lee's (1973) love styles including 'Storge', a companionate and friendship-based love where individuals cared deeply about each other and also 'Agape', where individuals put the needs of their partner first. Both were evidenced when Joe put aside his own distress to support his wife emotionally in a difficult situation. This was comparable to Maslow's B-Love which was defined as 'equal', 'unselfish' and 'giving' and no participant displayed D-love which was defined as 'selfish' and 'possessive'. The findings indicated that love for people with a learning disability could be defined by the same criteria as adults without a learning disability as outlined in Section 2.3.

However, this may not be acknowledged by some due to a perceived difference between 'us and them'.

### **7.3.2 Dependability**

People with learning disabilities face challenges which perpetuate their perceived differences. People with learning disabilities are both protected and disabled by society. They are 'protected' in that they are typically guaranteed the security of a place to live and receive financial support in the form of benefits. They are disabled by a lack of empowerment, decreased opportunities for employment and limited accommodation options (see Section 7.2). Participants in this study had less concerns regarding aspects of their 'safety and security needs' (for example it is unlikely they will become homeless), however they were disadvantaged in the opportunities available to them for developing the attributes associated with 'self-esteem needs' such as respect and achievement. It was likely that fewer people with learning disabilities would have concerns around the security of a place to live as non-disabled adults and therefore have a different understanding of the term 'dependability' in relation to their peers without a learning disability. Dependability was important to participants in terms of having a partner who was reliable and available to them, which was unsurprising considering how many had been let down and abused by others (as discussed in Chapter 4). Attachment theory places the dependability of the primary caregiver as fundamental to the development of secure attachments, the failure to be consistent results in insecure attachment styles as identified by Ainsworth *et al* (1978) and discussed in Section 2.3.5. All of the participants desired a consistent commitment from a partner and this was either stated explicitly or implied through the commitment of marriage or intention to marry. Maslow's theory linked relationships to security, but this appeared to be more related to the security of social status and possibly wealth. It could be interpreted that for my participants, the security provided by their relationships predominantly correlated with the description of security in attachment theory, which was having someone consistently available to them, responsive to their emotional needs, caring and affectionate. The case of SK (2008) defined marriage as a long term and complex commitment, one that she was unable to meet due to her limited understanding despite her attachment to at least one of her partners. Despite their learning disabilities, most of the participants appeared able to understand and make such a commitment and depended on their partner to do the same (with some possible exceptions that are discussed in Section 7.4.1).



The typology (Appendix 1) highlighted how women without learning disabilities value dependability, which was defined as sufficient wealth and financial security to support a family (Lacey *et al.*, 2004). Only Dean had children; no other participant planned to have children. This possibly affected why these 'dependable characteristics' were unimportant to participants. The notion of a male 'providing' for his family was a traditional role developed in a shared history and society within which women with learning disabilities were not traditionally included. There are fewer parents with learning disabilities compared to the general population and Emerson *et al.*'s (2005) survey identified that just 7% of those interviewed had children, with only 52% of these parents looking after their children.

Negative stereotypes persist that people with learning disabilities are incapable of parenthood (McConnell and Llewellyn, 2005). This is evident in statistics demonstrating that 50% of parents with learning disabilities have had their children removed into care (Tarleton *et al.*, 2006). In safeguarding proceedings poor parenting ability was commonly attributed to learning disability, with limited consideration afforded to factors such as poverty and social isolation experienced by parents (Booth *et al.*, 2005). 'Systems abuse' and 'institutional discrimination' were reported as prevalent within the legal system towards parents with learning disabilities (McConnell and Llewellyn, 2000). Parents reported being treated unfairly and having difficulty understanding the legal system and child protection proceedings (Booth and Booth, 2003, McConnell and Llewellyn 2005). A lack of clarity existed regarding the required standards for parents to achieve. Parents had to provide adequate care however 'there is no agreed definition of adequate care, with the legal interpretation being left up to individual practitioners' (Gould and Dodd, 2014, p. 25). Such barriers could discourage people with learning disabilities from parenthood, preventing them from attaining a socially valued role and experiencing a child's love, and both have benefits for meeting 'self-esteem needs' and 'love and belonging needs'. Consequently, the 'presumption of incompetence' identified by Booth (2000, p.176) possibly remains held by some professionals despite the Mental Capacity Act 2005.

Other factors posed further barriers to parenthood for people with learning disabilities. They are more likely to experience poverty, isolation, poor housing and unemployment (Emerson *et al.*, 2005), abuse (McCarthy, 1999) and have additional needs arising from issues such as poor mental or physical health (SCIE, 2005). My participants experienced similar issues (see Table 7). Parents with a learning disability have been

shown to cope better if they have good social support (Stenfert Kroese, *et al.* 2002). However not all parents possess this and isolation has been commonplace (Booth and Booth, 1998, McVilly *et al.*, 2005). People with learning disabilities reported opposition and scrutiny when revealing their pregnancy to families and professionals (Shewan *et al.*, 2012). Support for parents from local authorities' varied and parents often received inadequate support due to poor interagency working (Working Together with Parent Network, 2009). Mainstream parenting services were not always appropriate and children's social workers often had limited experience working with people with learning disabilities (Tarleton *et al.*, 2006).

My findings were consistent with McConnell and Llewellyn (2005), in that women had low expectations of their ability to parent. Considering issues discussed here, it was unsurprising that parenthood appeared undesirable for my participants, which possibly demonstrated a high level of insight into their own capabilities as potential parents. Parents with a learning disability face significant challenges to parenthood. It was possible that participants were aware of the issues which then overrode any maternal/paternal feelings. It was possible that staff may have been influenced by similar knowledge and deterred people from parenthood, fearing their inability to cope or injustices within the system and wanted to spare them the pain of having children removed.

### **7.3.3 Physical Attractiveness**

Forming a loving attachment was of most significance for participants, and physical attractiveness was not significant in terms of partner selection and the formation of loving relationships for people with learning disabilities. In research relating to people without a learning disability (see Appendix 1) there was a theme for female participants to value personal characteristics over physical beauty (Schmitt and Buss, 2005 and Levitt, 2006). Many male participants also valued personal characteristics over physical beauty, although some studies have demonstrated that men valued appearance more highly (Shackelford *et al.*, 2005 and Andrinopoulos *et al.*, 2006). Physical appearance was valued by my participants but it did not appear to be the most important aspect when selecting a partner. Participants appeared to have a more open approach to what they found attractive. Male participants did not discuss stereotypical ideals of female attractiveness such as slender bodies and large breasts (Singh and Young, 1995). The stereotypical ideals are not so easy to define but could include aspects of height and

muscle definition (Weeden and Sabini, 2005). Most female participants did not discuss such features when describing an ideal male partner, except for Mary who described her partner as 'strong'.

Participants' responses concerning what they found attractive mainly centred on facial aspects such as smiles and eyes. As discussed in Section 2.2, people with learning disabilities were mainly excluded from the sexual revolution in the 1960s and have not traditionally been considered attractive by society (Groce 1997). It was therefore possibly less surprising that they did not value physical attractiveness as highly. Some aspects of physical attractiveness, such as a nice smile, that were valued by participants in this research could be considered as outwards indicators of an internal quality such as kindness or happiness. Despite no males mentioning the stereotypical ideals of female attractiveness, females did discuss their concerns regarding their own attractiveness. Mary, Caroline and Carrie discussed dieting and felt they were overweight and wanted to change aspects of their appearance, thus demonstrating that it was not just women without a learning disability who feel pressure to conform to society's ideal of beauty. Research by Ahern *et al.* (2010) also confirmed that women with learning disabilities felt pressured to be slim and that participants demonstrated 'acute awareness of how thinness is idealised within their society, particularly in the mass media' (p.72). All of the female participants (excluding Emma) appeared overweight to varying degrees. Almost all of these women identified that they were receiving some support to lose weight but it was unclear who made the decision and how this topic was broached with individuals. It was also possible that their Depo Provera contraception contributed to their weight gain, with typical use resulting in a 5-8lb weight gain in the first two years (Netdoctor, 2011). Brown and Hams (1989) argued that women who experienced poor parental care could develop low self-esteem and a negative self-concept as poor parenting limited their resilience to such threats. This suggested that if people with learning disabilities (such as Caroline) internalised society's perception of them as unattractive it could reduce their confidence and feelings of acceptance, thus limiting their ability to meet their 'self-esteem needs' and possibly finding love.

In summary, participants were more open to what constituted someone being 'attractive', with less focus on 'stereotypical' ideals as identified in research for individuals without learning disabilities (Singh and Young, 1995, Weeden and Sabini, 2005). This may have provided participants with a wider range of potential partners and

individuals deemed 'less attractive' by stereotypical ideals could be less likely to be disadvantaged as a result. However, as discussed in 7.2, some participants had limited social circles and may have selected a potential partner due to availability rather than selecting a partner based on desired attributes, which was representative of the love style 'Pragma' (Lee, 1973). The same may apply to physical characteristics: if people had a wider range of potential participants they may have had the opportunity to be more selective when choosing a potential partner. People with learning disabilities could be considered less 'shallow' than people without learning disabilities due to a minimal interest in physical attributes. However, it could also be argued from the participants' narratives that both physical appearance and personality were of secondary importance in comparison to love and companionship. The need to have someone to be 'special' to and to be loved by was considered more important than physical attributes and attraction. It could be interpreted that the emotional benefits and reparative nature of having a person who loved you and was available to you outweighed physical deficits.

#### **7.3.4 Sexual Relationships**

Maslow's theory considered sex a 'basic physiological need'. My findings do not support this, affection as a physical demonstration of love did appear to be fundamental to relationships. Holt *et al.* (2009) suggested there were different levels of intimacy, which included physical, emotional or intellectual intimacy. All of the participants experienced some level of intimacy with a partner and my findings concurred with Jamieson (1999) and Rasmussen and Kilborne (2007) in that intimacy strengthened existing emotional closeness even if this was not fully sexual. My findings suggest that relationships where participants had lower verbal skills perhaps had higher levels of physical or emotional intimacy to compensate for the lack of language. It could be inferred that participants who had poor attachments within childhood considered physical affection reparative. Brennan *et al.* (1998) emphasised how infants utilised physical affection from primary caregivers as an indicator of safety. It could be interpreted that my participants utilised physical affection as a form of security, physical affirmation that their partner loved them. Physical affection was possibly a way to demonstrate to those with poor childhood attachments that they were wanted. Almost all of the participants said they felt loved by their partner and referenced physical affection as an indicator of this. Physical affection within a relationship could assist individuals to meet their 'safety and belonging needs' as well as their 'love and

belonging needs’.

Physical contact was found to increase intimacy and possibly strengthen attachment if a couple has close emotional bonds (Rasmussen and Kilborne, 2007). Five of the seven couples within this small convenience sample were in a sexless relationship (did not include sexual intercourse). This was a higher percentage compared to adults without a learning disability, which was approximately 15-20% (Flagg, 2012). There was no data available to determine how my findings compared to the national average for people with learning disabilities. Both of the couples within the research who did have a sexual relationship that included sexual intercourse and the couple who unsuccessfully attempted sexual intercourse were younger couples (under 35 years old). Older couples in my research did not have a sexual relationship which suggests that older couples with a learning disability may be more likely to be involved in a sexless relationship. Research has highlighted that older adults without a learning disability were less likely to be involved in a sexual relationship compared with younger adults and this was often related to physical ill health or sexual dysfunction (Lindau *et al.*, 2007). This implies they had been sexually active but had now ceased unlike the older participants in this research with a learning disability who had never been sexually active. The available literature also implies that people with learning disabilities were more likely to be in sexless relationships than adults without learning disabilities because of the barriers they faced from staff and society (Lesseliers, 1999; Kelly *et al.*, 2009).

There have been significant social, historical and cultural changes since the sexual revolution of the 1960s (see Section 2.2). The UK has become less sexually repressed, with increasingly liberal attitudes towards same-sex relationships, sex before marriage and casual sex (NATSAL, 2001-02). The progression of attitudes outlined in Section 2.2 has influenced social policy and practice in relation to people with learning disabilities (see Chapter 6). However, it could be argued from the sample in this research that people with learning disabilities have not progressed at the same pace in terms of sexual liberation as their peers who did not have a learning disability. Possible evidence to support this came from older participants such as Mary, with past restrictions from her family and society still appearing to dominate her thinking. Her comments ‘it’s alright isn’t it’, used by her three times when discussing kissing and cuddling her partner, provided a powerful example. It was revealing that she felt the need to ask permission to engage in such private acts and the anxiety and fear she

apparently felt that was associated with this. It appeared that these developments in relation to sex possibly came too late for the older participants.

The UK can be seen as less progressive compared to some European counterparts regarding attitudes towards sex for individuals with a learning or physical disability. 'Sexual Assistants' provide a legal service to disabled people to experience sexual pleasure and sensuality in European countries such as the Netherlands and Germany, but there is no such legal support role within the UK. There is a British organisation called the TLC Trust that provides services to people with learning disabilities and/or physical disabilities including links to specialist escort services, sexual therapy, erotic massages or striptease. The Netherlands runs a scheme where disabled people are entitled to have sexual relations funded by the government up to twelve times a year and a UK disabled man is campaigning for a similar scheme (Davis, 2013). My findings suggest that professionals, such as social care providers, teachers or community nursing teams, are still doing little to promote positive sexual relationships and there is a lack of specialised services available in the UK to signpost individuals who may require assistance in relation to sex, such as Carrie and Joe. The UK could benefit from more organisations like the TLC trust and a more liberal attitude to sex before people with learning disabilities can really express love with the same equality as people without learning disabilities.

## **7.4 Maintaining a relationships as an adult with a learning disability and the potential barriers**

Section 7.2. considered how people with learning disabilities found love. Section 7.3 explored what people valued in a potential partner. This Section considers how people with learning disabilities maintain a relationship and the potential barriers they may face in achieving this.

The Family Planning Association's *'It is My Right'* (2008) campaign highlighted that 94% of social care professionals thought barriers existed which prevented people with learning disabilities from having relationships. Researchers such as Kelly *et al.* (2009) concurred with this. My research highlighted the potential barriers to participants maintaining relationships (see Section 5.3) which parallel the various research findings presented within Section 2.4. However, the most significant barrier faced by participants in maintaining relationships was internal, including their experiences of

abuse and rejection. On reflection, this had more impact than external barriers such as resistance from parents or support providers. This Section will discuss both the potential external and internal barriers to maintaining a relationship for people with learning disabilities.

#### **7.4.1 Staff**

The literature review highlighted issues surrounding a lack of privacy for couples living in group homes (Hollomotz, 2008) and a fear that their relationship would not be supported by provider companies' policies (Lesseliers, 1999). These studies were completed over nine years ago, however, more recent research has highlighted that individuals with a learning disability could still face restrictions from support providers when attempting to engage in physical relationships (Kelly *et al.*, 2009 and Bane *et al.*, 2012).

My findings concurred with participants' reports that staff exerted control over them in ways that included not being able to share a bed on weekdays and having to ask for permission for a partner to move into their bedroom. This exertion of control implied that participants were not seen as autonomous adults, keeping them at the lower level of Maslow's (1943) hierarchy of needs by not respecting their choices. However, despite participants experiencing some restrictions, they were not stopped from engaging in relationships, unlike participants in Kelly *et al.*'s (2009) and Bane *et al.*'s (2012) research. Staff supported and encouraged participants to develop and maintain relationships with partners. This mirrored the findings of White and Barnitt's (2000) research. Staff supported couples to marry, to move in together, to access family planning services and by arranging dates. It was positive to observe people being supported in this way.

Rodgers (2009) the significant role staff and carers had a significant role in maintaining relationships by prompting contact for the individuals who are unable to do this for themselves due to their disability. This resonated with the stories of participants with higher support needs such as Mary and Peter where staff played an active role in the development of their relationships (see Section 5.3.3). Without this support from staff, participants such as Mary and Peter's relationships would probably not have continued due to their disability. Participants like Mary relied on staff input to organise dates and maintain aspects of her relationship.

There has been relaxing of attitudes regarding sexuality since the 1960s, as highlighted in Section 2.2, and this has influenced policy and practice towards sexuality for people with learning disabilities as outlined in Chapter 6. Since the 1980s there has been increased focus on supporting people with learning disabilities rights to have sexual relationships (McCarthy, 1999) and this was reflected in Government initiatives such as *Valuing People (2001)* and *Valuing People Now (2009)* and legislation such as the CQC's *Essential Standards* encouraged relationships for people with learning disabilities. Staff's exposure to both the changes in culture and attitudes in a post war society (as described in Section 2.2) and changes in social policy and practice (see Chapter 6) possibly contributed to the rise in the number of relationships within the past ten years for participants. It was also possible that prior to the Mental Capacity Act 2005 some participants (such as Alan and Peter) who had higher support needs compared to other participants were encouraged into marriage, due to staff's well-meaning desire to facilitate relationships without a full understanding of the implications. The legal case of SK (2008) demonstrated the complexities of an individual's capacity to consent in regards to relationships and the law. The judge ruled that she lacked a full understanding of marriage, in that she lacked the capacity to make such a long-term and complex commitment to another individual. It was possible that there was a weakness on my part in extracting this information in the interviews but my discussions with Alan suggested that his marriage did not fulfil the definition of a 'long-term and complex commitment to another individual'. It was possible that Alan lacked the ability to state why he loved his wife or to demonstrate a complex commitment to her due to his learning disability. Their lives appeared separate in some ways such as having individual bedrooms and not sharing a marital bed. It could be interpreted that marriage was perhaps too complicated a concept for Alan to understand or express due to his disability. Peter also displayed a lack of understanding for complex situations such as a marriage breakdown, which again appeared related to the embodied reality of his learning disability and its impact on his cognitive abilities. Peter appeared unable to understand the complexities of his marital breakdown and relied on staff to guide him and his wife through this complicated process. Staff removed him from their home as he was experiencing difficulties understanding what this change meant for them as a couple. This differed from couples with lower support needs such as Caroline and John who were able to address issues within their relationship. For example, John moved from their shared flat as he wanted more space and Caroline accepted this. One support worker stated that an ex-staff member had encouraged Peter's marriage but felt that now the couple would be



deemed as lacking capacity to make the decision to marry. Mary required daily assistance to travel, attend her personal care needs, prepare food, maintain her home, manage her money and her health. Capacity should always be presumed however it was unlikely that Mary would have the capacity to understand the complex commitment required to marry or possibly engage in a sexual relationship.

This discussion demonstrates the complex role that support staff have in the maintenance of relationships. Staff may be encouraging of relationships but when complexities arise such as conflicts or breakdowns in the relationship, staff are required to address the issue as participants may be unable to do due to their disability. Staff have to achieve a balance between protecting the individual from harm (as bound by their duty of care) and enabling them to engage in relationships while still considering their capacity to make decisions. Despite some restrictions from staff, they seemed to have acted as facilitators of relationships at times, however, in some cases this was possibly done at the expense of participants' capacity to fully understand the commitment they were making. Despite this, staff played a central role in supporting people to make loving attachments, and this was achieved by supporting individuals 'safety and security needs' such as physically supporting participants on dates, resolving issues among couples or safeguarding individuals from abuse. Staff also supported participants in meeting their 'love and belonging needs', examples included supporting them to maintain contact with partners and friends and providing emotional support regarding relationships. Additionally, staff performed a key role in supporting people to increase their 'self-esteem needs' such as independence and autonomy by facilitating with the process of people getting married and moving into their own flat. Considering Maslow's theory, staff were assisting people to meet many of their 'needs'. This highlighted the important role of support staff and how people with learning disabilities remain dependent on good support from staff in regards to finding and maintaining love.

#### **7.4.2 Service Providers**

My findings highlighted the influence staff exerted on the development and maintenance of relationships for people with learning disabilities. However, it is not possible to see staff in isolation without considering the impact of the service providers which employ them.

Organisations produce the policies which staff adhere to, and these should be based on regulatory guidance such as *Essential Standards for Quality and Safety* (CQC, 2010), strategies such as *Valuing People* (DoH, 2009) and initiatives such as the '*Driving up Quality Code*' (Driving up Quality Alliance, 2013). Organisations that provide superior support devise policies which incorporate the guidance outlined in such documents/initiatives and provide training to staff regarding their practical implementation. *Essential Standards for Quality and Safety* (CQC, 2010), *Valuing People* (DoH, 2001) and the '*Driving up Quality Code*' (Driving up Quality Alliance, 2013) actively support the development of relationships for people with learning disabilities, as well as encouraging people to take 'informed risks, while balancing the need for preference and choice with safety and effectiveness' (CQC, 2010, p.44). Organisations which adhere to such guidance demonstrate good values and best practice.

I had links with both organisations prior to the research, and based on my professional knowledge and experience, considered both to demonstrate best practice. I was aware of this preconception and ensured I reflected on this during my analysis to limit unconscious bias. However, I found little evidence to dispute this claim. Based on staff observations and participants' data, Provider 1 appeared to have robust policies in place which were demonstrated via staff practice, this was evidenced in people being supported to take informed risks, such as Carrie and Joe getting married, Kerry moving to her own flat from a care home and Emma beginning a sexual relationship considering her past experiences. Provider 2 demonstrated less informed risk taking, however, this possibly related to the embodied reality of Mary and Peters' learning disabilities as they were more limited in the types of risks it was possible to engage in. However based on the needs of the participants supported by Provider 2, it could be argued that they were demonstrating similar patterns to Provider 1 in that Peter was married and Mary spent time alone in her bedsit with a partner engaged in physical affection, if not penetrative sex. Staff appeared committed to supporting people to engage in relationships. However, it is possible that in organisations where relationships are afforded a lower priority people may be excluded. As discussed in Section 7.4.1, due to the embodied reality of some individuals' learning disability, they are more likely to rely on staff to facilitate relationships (Rodgers, 2009) as they do not possess the organisational or communication skills required.

Organisations have a responsibility for the service design (unless this was an individual

flat) and this includes providing private spaces. Both organisations reflected good values and best practice by supporting couples to experience privacy, independence and respect as directed by *Essential Standards for Quality and Safety -Outcome One-Respecting and Involving Service Users* (CQC, 2010). This was in contrast to organisations included in Hollomotz's (2008) and Royal College of Nursing's (2011) research where privacy was not respected and this appeared an organisational issue rather than down to individual staff members. During the interviews I witnessed staff respecting peoples' privacy such as people having their own locked bedroom door. However, as identified by Hollomotz (2008), housing providers did not always provide a double bed for participants in my research. Mary's bedsit only contained a single bed and provided no space for an overnight guest. It may be possible that staff did not consider Mary an adult who may wish a partner to stay overnight or possibly just that the housing provider could have been challenged to consider alternative options that would have allowed her a double bed.

Participants lacked real choice in other areas of their lives, e.g. where or with whom they lived. This was not controlled by the support provider but by commissioners, social workers or the Department of Work of Pensions (if the issue was financial such as with Dean and Kerry). This was reflective of Fyson *et al.*'s (2007) research where participants were excluded from making life-altering choices such as where they lived or who they lived with. As discussed above, for some participants the reality is that they would be unable to live alone as a couple due to their disability. Even if this was possible, due to their needs they would require continuous support from staff so would never live 'truly alone' as a couple. Both Joe and Carrie and Liam and Emma expressed a desire to live alone as a couple but were unable to do so at the time of their interview. This did not seem to be their choice. It could be argued that support providers have an obligation to advocate on behalf of those they support by championing their individuals' rights and where possible challenge commissioning practice and social workers if accommodation is identified as unsuitable. Ideally, all of the participants should have the choice to decide who they live with and receive individualised support to express their views.

### **7.4.3 Having a learning disability**

My research demonstrated that having a learning disability did not stop participants finding or maintaining a relationship. Attachment theory defined love a 'basic need'

(Bowlby, 1969, 1973 and 1980), and this implied that everyone could love and be loved regardless of their level of impairment. Maslow argued that love was a 'higher psychological need', and this could be interpreted as only something that those with an understanding of psychological abstract concepts could attain. My research did not include people with higher support needs (potentially classified as having profound or severe learning disabilities) such as those who do not use speech to communicate or lack an understanding of abstract concepts such as love. Therefore it is not possible to discuss how people with higher support needs defined/experienced love or how the existence of a learning disability mediates the types of relationships such individuals experience. As they were not included in the research any discussion would be merely speculative. However, the findings suggested that people were on a continuum of varying levels of disability and that the embodied reality of their learning disability mediated the types of relationships it was possible for participants to have.

As discussed in Section 7.2, Gardner (1983) defined interpersonal and intrapersonal intelligence as the ability to understand the behaviours of others and oneself. Based on this definition participants with lower support needs such as Liam, Emma, Joe, Carrie, Kerry, Caroline, John and Dean displayed higher levels of interpersonal and intrapersonal intelligence in interviews compared to Alan, Peter and Mary. Jamieson (1999) stated that for intimacy to occur there had to be a level of mutual engagement between partners. Reciprocity was identified as important in the maintenance of a happy relationship (Buunk and Schaufeli, 1999). Rubin (1970) discussed a similar concept when defining the key components of love that included caring and putting others needs first. This concurred with Lee's (1973) love style 'Agape' that focused on a 'selfless love', with the desire to take care of a partner and unconditional love. Despite their learning disability, Liam, Emma, Joe, Carrie, Kerry, Caroline, John and Dean's relationships displayed elements of both Rubin's (1970) and Lee's (1973) concepts, as well as elevated levels of mutual reciprocity within a culture of 'supporting each other'. Despite having a learning disability, these participants were able to engage in the complexities of a relationship such as supporting one's partner and behaving altruistically towards them. Such behaviour reinforced participants' desire to be 'special' to another person, and provided someone who could support and cared for them in various ways, especially when this had been absent in some participants' lives (as discussed in Chapter 4). The embodied reality of having a learning disability was that participants required support with daily tasks, and some couples with lower support needs discussed how they could negate the need for staff support by assisting each

other. For example, Kerry has problems with her vision and Dean supported her to travel rather than staff and Joe supported Carrie in a police interview following a reported case of sexual abuse. Based on what was stated in interviews, participants with higher support needs (such as Alan and Mary) had these needs met exclusively by their support staff. This indicated that, due to the complexity of their support needs, some participants lacked the ability to fully engage in reciprocal relationships and provide the type of support that Joe and Dean afforded to their partners.

It could be hypothesised that participants who demonstrated less reciprocity and emotional intelligence, such as Mary, could possibly have been on the autistic spectrum. Baron-Cohen *et al.* (1985) identified that people with autism lack 'theory of mind' which is the ability to understand others' emotional states. Autistic peoples' relationships have been defined as lacking sharing and reciprocity. This impacted on an individuals' ability to form a secure attachment, and they rarely experience love relationships (Howe, 1995). Autism rates are higher within the learning disabled population compared to the wider population, 60-70% of people who have an autistic spectrum condition have a learning disability (Brugha *et al.*, 2012). As I did not request any pre-information from the provider organisations I was unaware if any participants featured on the autistic spectrum, but if they had been this could have influenced participants' ability to form the types of reciprocal relationships identified by Rubin's (1970) and Lee's (1973) research, however, there was nothing to suggest to me as a professional that any of the participants had autistic traits that might stop them forming loving attachments.

The relationships for people with lower support needs demonstrated significant diversity. All of the relationships had faced difficulties and adversity but the participants were able to overcome them with the support of their partner. Some of my participants had higher support needs than others and it was evident that their relationships did not demonstrate the same level of depth or diversity as the relationships of the rest of the participants. It is the reality that due their learning disability and associated support needs they did not have the same level of exposure to challenges and, therefore, their relationship was not 'tested' in the same way. They were more protected by staff who met their 'safety and belonging needs' and who had a more central role in their lives (such as dealing with conflict and organising social activities). Some difficulties faced by participants were unique to being an adult with a learning disability, such as restrictions from staff (Section 5.3.2), their group home living situation (Section 5.3.1),

higher levels of abuse (Section 4.2.3) and segregation from society (Section 5.1.1 and 5.1.3). However, they shared other difficulties in common with the general population, such as poverty and lack of employment (Section 7.2), isolation (Section 5.1.1), dealing with a partner's complex past (Section 4.3.1 and 4.3.3) and the negative influence of family and friends (Section 5.4.1 and 5.4.2). Participants with lower support needs were able to overcome issues, implying that they negotiated the problem together and decided to continue with the relationship. Examples include the way that Emma and Liam's relationship continued despite reported jealousy from a housemate; Carrie and Joe overcoming the interference from Carrie's ex-partner; John moving out of his flat with Caroline to have more space; and Dean and Kerry being able to negotiate their living situation to best suit their finances. Participants' lives shared many of the same complexities as those without learning disabilities, but what was more obviously different were some of the challenges they faced as a couple.

The ability to negotiate issues was central to maintaining a relationship for individuals with lower support needs. This was less important for those with higher support needs as this role was often addressed by staff. An example of this included how staff had to intervene to manage Peter and his wife's separation. It was possible to infer that the embodied reality of having a learning disability impacted upon the types of relationships it was possible for participants to have. However, we can only provide some form of value judgement since we do not have access to validating user experiences from our own perception of the impact that learning disability might have on them and their lifestyles. Regardless of participants' disability, they all experienced love with a partner who cared about them and this was important to all participants.

#### **7.4.4 Neglectful Experiences and abuse**

The companionship that their partners provided was more important to participants than sex and attraction, thus supporting attachment theory's claim that love is a 'basic need' (Bowlby, 1979), as opposed to Maslow (1943) who considered sex a 'basic need' and love a 'higher psychological need'. Participants appreciated having someone to share their lives with, to participate in activities with and to have someone care about them. This was reflective of Rubin's (1970) theory of love where individuals valued having someone special to be close to and who was exclusively theirs'. This was understandable considering the rejection and abandonment experienced by various participants (as discussed in Chapter 4). All of the participants shared the same 'basic

need' to be loved. This was universal, regardless of age, family background or social networks. Maslow (1943) claimed that deficiencies in this basic level in childhood as a result of neglect, abuse, separation etc. could impact on an individual's ability to form relationships. Participants' current relationships and the love and sense of belonging they experienced appeared reparative following their difficult experiences in childhood. All of the participants wanted a partner who was 'nice' and 'kind' and they valued partners who reflected these traits. There was a similarity between these attributes and those of a caregiver where a secure attachment could be made (i.e. an emotionally available, responsive and caring mother). As stated in Section 4.3 some participants may have had issues surrounding attachment. It was possible they were unconsciously searching to recreate what they lacked in childhood.

Research has identified the difficulties survivors of abuse experience in forming long-term relationships (DiLillo and Long, 1999 and Marendaz and Wood, 1999). DiLillo and Long (1999) identified that women who had suffered sexual abuse in childhood experienced 'less relationship satisfaction, poorer communication, and lower levels of trust in their partners' (p.59). Only one female participant had experienced sexual abuse in childhood, but two female participants had experienced it in adolescence. All of the participants claimed to have high levels of trust in their partner, regardless of whether they had experienced abuse or not. Wind and Silvern (1992) identified that women who had been sexually abused were more likely to engage in sexually or physically abusive relationships in adulthood. This was not a pattern replicated by participants in my research to my knowledge. This may have been due to the staff protecting them and upholding their 'safety and security needs'. Reavey and Gough (2000) argued that a narrative exists within research surrounding sexual abuse that places emphasis on the female's sexuality being 'different' or 'abnormal' and fails to explain how 'choices' in relationship can differ for a survivor of childhood sexual abuse based on their experiences and expectations. Kerry had experienced sexual abuse by her father as a child which could have resulted in low expectations for her adult relationships. However, Kerry was a survivor of abuse and was adamant she would not be subjected to sexual abuse as an adult and terminated a relationship due to sexual pressure from a man.

Walker *et al.* (2009) identified that negative experiences in childhood could impact on adult relationships. These experiences included 'neglect, dysfunctional or unhealthy, family-of-origin patterns such as witnessing domestic violence, parental marital discord

and stressful family-of-origin circumstances' (p. 398). This view was supported by both attachment theory (Bowlby, 1979) and Maslow (1943). Both theories proposed that individuals who felt safe in childhood (met their 'safety and security needs'/ formed a secure attachment) would be better equipped to overcome negative experiences such as abuse. Walker *et al.* (2009) suggested that more negative experiences in childhood could lead to negative patterns in adult relationships. A number of participants within my research shared similar negative experiences to Walker *et al.*'s (2009) participants (see Chapter 4 and Sections 5.4.1 and 5.4.2). However, the level of impact the negative experiences had was based on the individual's attitudes. Walker *et al.* (2009) argued 'the influence of the past could be magnified or diminished depending on present factors including attitude' (p. 403). Walker *et al.* (2009) suggested that participants who were happy with their present situation were able to use this to diminish the negative effect of the abuse. Some participants appeared to have achieved this more successfully than others. This may have been related to having a good attachment with one primary care giver (Bowlby, 1988) or alternatively defined as having their 'safety and security needs' met in childhood (Maslow, 1943). For example, Emma experienced a serious sexual assault but with the support of her family and professionals she was able to overcome this and engage in a loving sexual relationship with Liam. Other participants appeared less able to overcome such experiences, such as Kerry who was abused by her father and stepfather and appeared less enthusiastic about her sex life with Dean. Both attachment theory (Ainsworth *et al.*, 1978) and Maslow (1943) stated that it was the role of the primary care giver to ensure an infant is safe, and when the primary caregiver is the abuser it can be even more damaging (Howe, 1995). Kerry was the only person who claimed to have been physically/sexually abused by her primary caregiver and appeared less able to recover from her experiences, while Emma reported a loving and supportive childhood. Rutter *et al.* (1990) proposed that psychological support helps build resilience to trauma, and this can be from a loving adoptive family, good staff support or a partner. This suggested that the support networks around the person following the abuse were important in determining how likely it is that the person will be able to overcome these issues and not allow them to affect their present relationships. Kerry had multiple experiences of abuse (rather than a single episode) from multiple care givers which suggests that it was also the extent of the abuse which people suffer that led to its impact on adult relationships.

The only female participants who were engaging in sexual relationships (Emma and



Kerry) had been seriously sexually assaulted. Research has demonstrated that women who have been sexually abused were more likely to have a higher lifetime number of partners and engage in riskier sexual behaviour than those who had not experienced sexual abuse in childhood/adolescence (Senn *et al.*, 2007). Kerry's claim that she had had numerous partners in her life before meeting Dean suggested this type of risky behaviour. Bogaert and Sadava (2002) demonstrated a link between insecure attachments and a high number of lifetime partners. Bogaert and Sadava (2002) hypothesised that attachment could change in response to adult romantic relationships, however they were uncertain whether a secure attachment led to fewer sexual partners or if a good long-term adult relationship led to a secure attachment. My findings support the latter, suggesting that good long-term adult relationships could lead to a secure attachment. Kerry and Dean reported multiple partners and possible attachment issues yet seemed able to commit together to a loving long-term relationship.

Following her assault, Emma was only able to engage in a sexual relationship with Liam after sufficient trust was built and he was her only partner. It was unclear if any of the participants, other than Emma, were given the opportunity to talk through and receive support around their experiences with previous sexual abuse. The findings of Walker *et al.* (2009) suggested more should be done to ensure that past issues were addressed to minimise impact on adult relationships and suggested this could be achieved through therapy. Caroline and Peter, despite not having experienced sexual abuse, appeared keen to discuss their past which included incidents of rejection and abandonment (Section 4.3 and 5.4.2) with a person outside of their support staff. According to attachment theory, feelings of rejection and abandonment from a primary care giver have lasting impact on an individual's ability to form relationships (Ainsworth *et al.*, 1978 and Hazan and Shaver, 1987). It appeared that more significance was given to ensuring protection from and supporting individuals following sexual abuse and less priority was given to emotional well-being following psychological trauma. It seems that some professionals/staff have an attitude that as long as people's 'safety and security needs' are met, there is no further requirement to provide the required emotional support to enable individuals to meet their 'love and belonging needs', e.g. by having good intimate friendships, or meeting their 'self-esteem needs', such as having confidence and high self-esteem. Neither Caroline nor Peter appeared to have attained all of the higher levels of Maslow's hierarchy, possibly because of their negative previous experiences and possibly because their emotional needs had been neglected to some extent.

## 7.5 Chapter Summary

The research questions were ‘what do people with learning disabilities look for in a potential partner and how do their prior experiences affect their choices and influence the relationships they experience?’ The analysis of the interviews identified that this question was answered by exploring:

- What brings people with a learning disability together and holds them together?
- What prevents people with a learning disability from getting together or staying together?

Fundamentally, the participants with learning disabilities desired a kind, loving and affectionate partner who provided companionship. In agreement with attachment theory, love and affection appeared to be a ‘basic need’, but not sex as proposed by Maslow’s theory. Attachment theory considers love to be most significant aspect of relationships, as opposed to viewing relationships as a means to increase social status or security.

People with a learning disability’s definitions of what constitutes an ‘ideal partner’ focussed less on wealth, social status, attractiveness or employment status, when compared to research which examined partner selection for people without learning disabilities (see Appendix 1). People with learning disabilities appeared to value similar characteristics in a partner as people without learning disabilities (see Appendix 1), but expressed this in a different way based on their own experiences and shared history. For example, dependability was considered important but not in terms of wealth/social status but as being consistently available and having someone who responded to their emotional needs. This definition correlated with the description of security in attachment theory, and was understandable considering the abuse and rejection some participants’ had experienced.

In terms of finding love and maintaining a relationship, people with learning disabilities continue to experience substantial barriers. Despite advances and initiatives people still experienced prejudice, abuse and social isolation. Couples in this research faced adversity in relationships and were able to overcome it together. Society, rather than the individuals themselves, appeared to cause the barriers to forming and maintaining relationships. Participants still appeared restricted by a ‘risk culture’ that extended from policy makers to support providers and still faced direct restrictions from staff and families in relation to their relationships. The findings suggested that staff/

organisations may have paid more attention to meeting individuals 'safety and security needs' than supporting individuals to develop autonomy and, therefore, their 'self-esteem needs'. There was no sense that having a partner assisted participants to ascend Maslow's traditional hierarchy. Some participants, however, were restricted in their ability to ascend the hierarchy due to the embodied reality of their learning disability (such an inability to understand cognitive concepts or evaluate risk) and resulting higher support needs. Staff were legally obligated to restrict aspects of relationships to uphold 'safety and security needs'. Participants with higher support needs were reliant on staff for their social circles and the formation of relationships. Poor support in this area could have an impact on their ability to meet their 'love and belonging needs' and finding love.

The experience of these challenges demonstrated the commitment of couples to their relationship. Despite the issues faced none stopped participants from engaging in relationships. Chapter 8 will explain how the conclusions relate to my two research questions which will be presented with answers from: 1) a theoretical perspective underpinned by attachment theory and Maslow's theory and 2) an empirical perspective from which recommendations for the future can be drawn.

## **Chapter 8- Conclusion**

### **8.1 Introduction**

My research focused on the relationships of adults with learning disabilities and I sought to understand what they look for in a potential partner and how their prior experiences affected their choices and influenced their relationships. Employing a modified version of Van Manen's phenomenology I interviewed eleven people with a learning disability about their current and previous relationships. The purpose of this concluding Chapter is to outline the 'contribution to knowledge' of my research. This includes the limitations of my study and what I learnt in the process of conducting it. The knowledge and consequent suggestions are especially pertinent to those working with the field of learning disabilities, including social policy makers, social workers, educators and support workers. The Chapter will finish with my concluding thoughts.

### **8.2 Revisiting the key findings and contributions to new knowledge**

#### **8.2.1 Theoretical Perspective**

Research relating to people without a learning disability suggests a correlation between absent or poor relationships in childhood with a primary caregiver and poor relationships in adulthood (Ainsworth and Wittig, 1969; Bowlby, 1979; Hodges and Tizard, 1989; Franz *et al.*, 1991). This study is unique as my searches identified no previous research that examined the prior experiences of participants who had learning disabilities, including family background and relationships, to understand how it could affect their choices and influence the relationships they experience. This study is also unique as my searches have found no previous research regarding partner selection for people with learning disabilities. As a result of the research presented here a clearer picture has now emerged as to what people with learning disabilities value in a potential partner.

This is also the first study to examine partner selection for people with learning disabilities in relation to attachment theory and Maslow's theory of human motivation. These are two competing theories of human development which attribute different

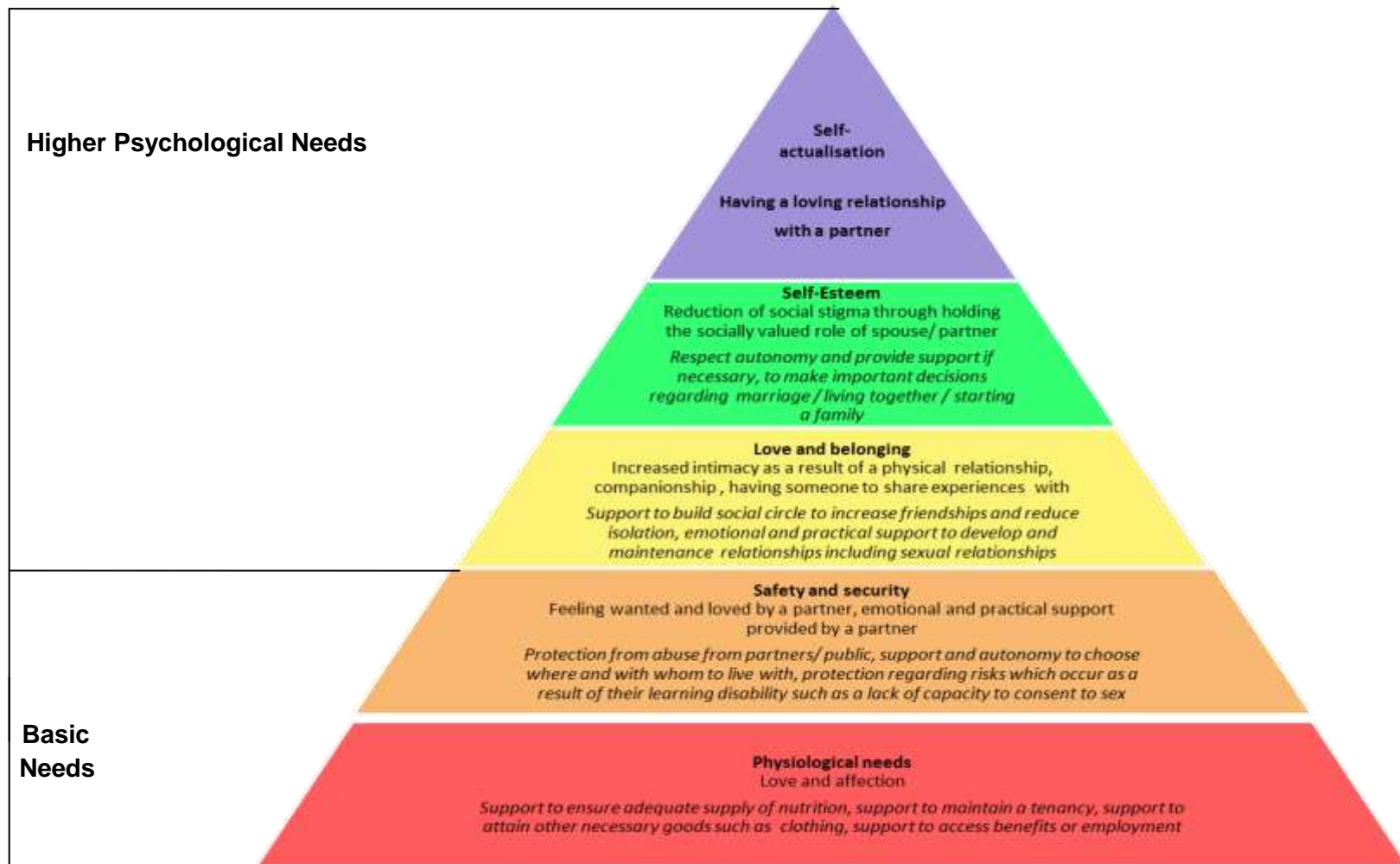
levels of significance to love and relationships. Attachment theory places the experience of 'being loved' as a 'basic need' (Bowlby, 1973). Maslow (1943) held an historical view of relationships as a means to increase security or social states and as a process to facilitate self-actualisation, not a 'basic need'. My initial view was that attachment theory appeared to have more validity in relation to the importance of love within relationships, due to the significance highlighted by various theories of love (Section 2.3.2), the emphasised need for intimacy (Section 2.3.3) and the weight attributed to secure attachments as a predictor of relationship success (Section 2.3.5). However, conducting the research demonstrated that both theories provided insight into understanding relationships for people with learning disabilities in relation to partner selection.

My most significant finding was the importance of love to participants, with all of the participants desiring a partner to love and who loved them; and being able to form a secure attachment (Bowlby, 1979) to another person. In line with attachment theory, participants appeared to consider love a 'basic need'. The traditional view of relationships as a means to increase security or social status was not supported, however there was evidence that this was a motivator in forming relationships but was ultimately less important than love. Based on my findings, sex was not considered a 'basic need' but affection was. Affection was linked to demonstrating love, especially for those with poorer verbal skills such as Mary. Therefore affection was considered fundamental, as it forms part of a loving relationship with an affectionate partner. Attachment theory proposes that relationship patterns developed in childhood persisted into adulthood (Ainsworth *et al.*, 1978). Maslow's theory is more flexible, stating that even if people had experienced deficiencies in any of his levels during childhood, they could still ascend/ descend the hierarchy at any age. There was evidence from my findings that despite experiencing poor relationships in childhood, participants were able to overcome attachment issues with the love of a good partner. There was no evidence to demonstrate that people in relationships had ascended Maslow's hierarchy. There was limited support for the concept of Maslow's hierarchy as a pyramid to be ascended over various levels, as participants met parts of various levels at different times. Despite this, there was evidence that the 'basic and psychological needs' as defined by Maslow (1943) were important to people with learning disabilities and their relationships.

Figure 3 depicts a revised model of Maslow's hierarchy that incorporates my findings,

demonstrating what having a loving relationship meant to the participants and, shown in italics, is what support they required from staff or families in order to ascend the hierarchy and form successful relationships.

**Figure 3: Revised Maslow's hierarchy: Forming intimate relationships as a person with a learning disability- what it means to them and the support required to achieve this.**



*Italics – Support required to ascend hierarchy*

## 8.2.2 Empirical Perspective

My research identifies that traits which are most highly valued in a potential partner were also those associated with a 'loving and secure' primary caregiver (Ainsworth *et al.*, 1978 and Hazan and Shaver, 1987). Participants' narratives showed a shared history of rejection and abandonment and, therefore, the availability and reliability of a partner was important to them when selecting a partner and maintaining a relationship. The better the relationship with the family/caregiver, the more stable and content their relationship with a partner was. Despite encountering issues within their past family relationships, participants were able to overcome this and progress to having stable and loving relationships (as discussed in Chapter 4), therefore not supporting the theory that poor childhood attachments with a primary caregiver equate to a poor relationships in adulthood (Ainsworth and Wittig, 1969; Bowlby, 1979; Hodges and Tizard, 1989). It may be that the desire to have a person to whom you are 'special' increases if this was lacking in childhood from a primary caregiver.

Loving and caring relationships were reparative for the participants who had suffered abuse (see Sections 4.2.3. and 5.2). All of the participants were able to avoid replicating the abusive patterns from childhood within relationships in adulthood, as identified by Walker *et al.* (2009). Partners who are kind and loving were highly valued by all of the participants. My findings contradict almost all of the previous research which has focussed on sexual relationships for people with learning disabilities (e.g. McCarthy, 1999, Lesseliers, 1999) in the way that my participants experienced loving physical relationships. Participants saw affection, not necessarily sex, as being fundamental to the relationship, which conformed to theories of love and intimacy for adults without learning disabilities (Berscheid and Walster, 1978; Rubin, 1970; Sternberg, 1996 and Holt *et al.*, 2009). My findings contradict Maslow (1943) that sex is a 'basic need' as participants' valued affection more. The relationships of the participants consisted of a significant amount of cuddling, hand-holding and kissing rather than vaginal or anal penetration (McCarthy, 1999). The participants were content with their level of physical contact (except one female who wanted more) and, unlike many other people with learning disabilities (McCarthy, 1999), received significant pleasure from it (Section 5.2.1). My analysis of social, cultural and historical changes in the UK post 1960 and policy/societal attitudes towards people with learning disabilities suggests this was at least partly due to the historic repression of sexuality for people with learning disabilities (see Section 2.2 and Chapter 6). The attitudes of younger



participants appeared more liberal and more passionate.

The key finding of my research was that participants' preferences and desires within relationships are comparable to the results of research on adults without learning disabilities (see Section 5.1). Participants with learning disabilities' descriptions of a loving relationship correlated with those for non-disabled adults, with all of them desiring tenderness and affection, intimacy, a caring partner, commitment and exclusivity as defined by Maslow (1954), Rubin (1970), Berscheid and Walster (1978), Sternberg (1996) and Graham (2011). Rubin (1970) and Sternberg (1996) identified that the desire to be 'special' to another person was universal and my study shows that this applies to people with a learning disability. Having a learning disability frequently places people on the periphery of society and the term 'special' often has negative and infantilising connotations such as 'special needs' (as Carrie describes in Section 5.2.2). My study reveals that being 'special' and loved by a partner is positive in this context, employed to reaffirm their 'normality', and that it assists in placing them back in mainstream society by enabling them to see themselves as an equal. There was evidence supporting Maslow's theory that having a partner increases social status and 'self-esteem needs', however this is of secondary importance to the love a relationship provided for the participants. Having a partner identified for the participants that they are 'wanted by another', which possibly explains why some participants desired symbolic gestures such as an engagement or wedding ring that is visible to society. There was great depth and diversity displayed within some of the participants' relationships. My research demonstrates that people with learning disabilities are ordinary human beings who face some additional challenges beyond their disability, including restrictions from staff (Section 5.3), social exclusion (see Section 2.2 and Chapter 6), poverty and lack of employment (Section 7.2). People with learning disabilities experience the same levels of adversity as people without learning disabilities and are able to overcome them and maintain a relationship (Section 7.4).

Barriers still exist to enabling people with learning disabilities to become fully engaged members of mainstream society. This was evidenced in this research by the participants speaking of their own dating culture which was distinct from the wider population, and almost all of the couples in this study met in segregated environments for people with learning disabilities (Section 5.1.1). This also demonstrates how poorly integrated this group is within their communities in 2014, despite increasingly liberal attitudes within society (Section 2.2) and various government initiatives and

developments in social care policy (Chapter 6). More positively, the younger participants appeared more integrated within society. This highlights a need to improve access to leisure and social activities for older people with learning disabilities, to assist them in finding love and ensuring they are not socially isolated (see Section 7.2.1). The research demonstrates the significant role staff play in the development and formation of relationships and how the quality of their support is central to the development of loving attachments. This emphasised how good support can facilitate and maintain relationships, while poor support inhibits their formation and maintenance. The extent of the support provided by staff relates to the embodied reality of their learning disability and associated impairments in cognitive ability/ adaptive functioning. When people have higher support needs (or deficits in certain skills) staff can play a key role in enabling individuals to meet the various 'needs' identified such as:

- Safety and security needs: Safeguarding individuals from abusive partners, organising/ physically accompanying people on dates, providing emotional support and contraceptive advice
- Love and belonging needs: Developing social circles and facilitating friendships, maintaining relationships/ family contact and negotiating conflict between couples/ housemates
- Self- esteem needs: Supporting individuals to progress in their relationship with issues such as marriage and moving home

To reflect on the conclusions of my research an alternative model that combined elements of both theories was developed (Figure 4). Maslow's 'basic and psychological needs were re-interpreted to represent key areas which could, if attained by people with learning disabilities, facilitate the formation and maintenance of intimate relationships. Figure 4 proposes a relational, as opposed to hierarchal, model of 'others' such as staff, family/ friends and organisations who are influential in terms of attaining needs. Unlike Maslow's theory, my proposed model is underpinned by the belief that relationships must be understood within a historical, societal and cultural context (see Section 2.2 and Chapter 6). The 'driver' outlined in Figure 4 is not 'self-actualisation', but rather the ability to form loving affectionate relationships with a partner as in attachment theory. Maslow's theory outlined two levels of 'basic needs' (see Figure 1A), but the 'basic physiological needs' were not included in this model, as, excluding sex, these needs are usually met for all in developed countries unless significant abuse is occurring.

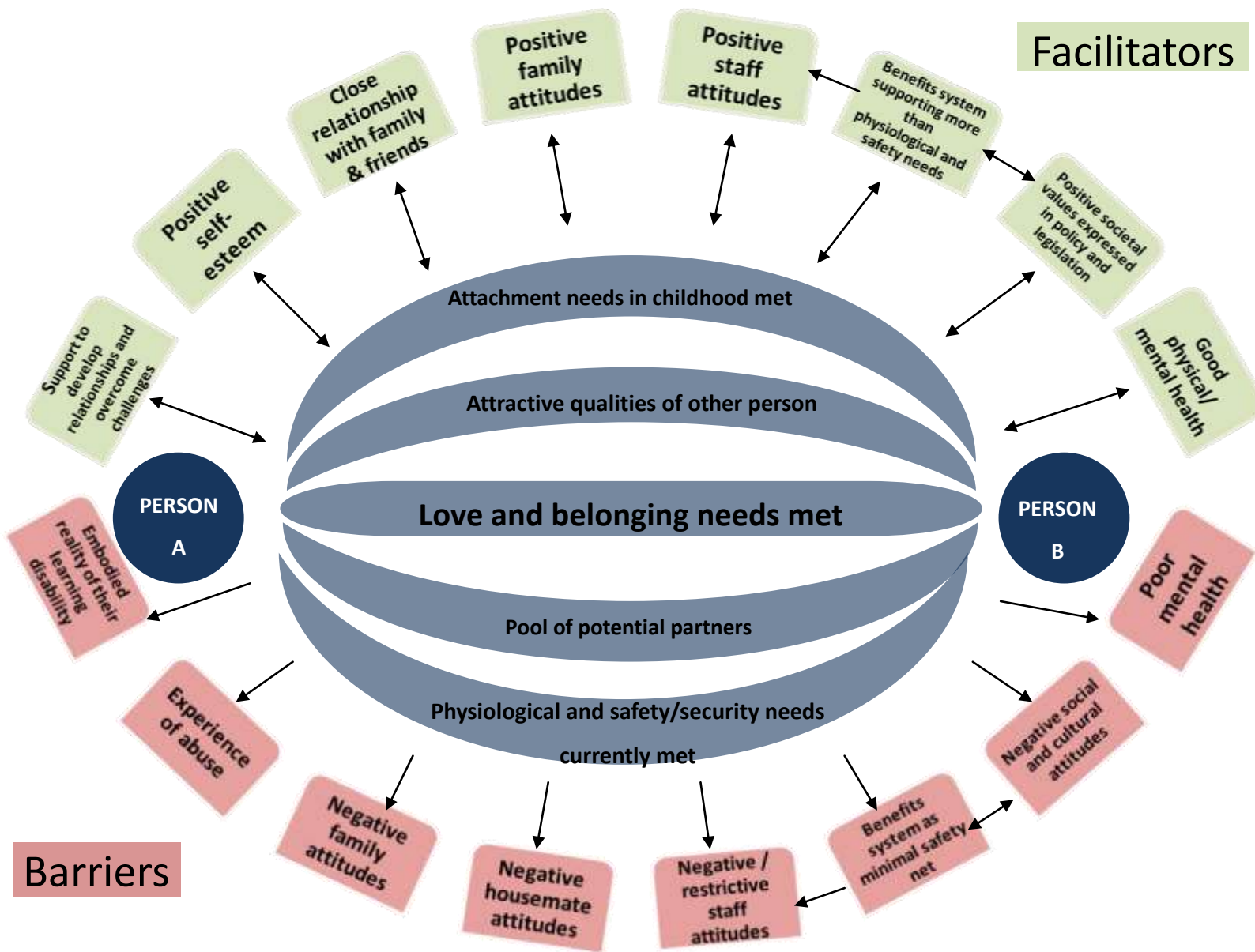


Figure 4: Relational model of facilitators and barriers to relationships for people with learning disabilities

## **8.3 Limitations of My Research and Implications for Future Research**

Various difficulties impeded this research at various stages and impacted on its overall findings. This Section examines the main limitations identified in the research and also outlines suggestions for further research which may address some of the limitations.

### **8.3.1 Recruitment of participants**

The main challenge encountered was the recruitment of participants as organisations were less willing to engage with the research than initially hoped. The reasons for this were unclear as they either failed to respond or claimed to not support any person who fulfilled the inclusion criteria. It was possible that they may not have wanted to give another social care professional (and possible competitor) access to their organisation and that this may have contributed to the lack of responses. Prospective gatekeepers would have known I was a fellow social care professional as my correspondence was sent from my work email. If I had sent correspondence from my university email account, I may have had more responses. Social care organisations are also under increasing financial pressure, which could have impacted on their willingness to engage in research. However, my sample size was congruent and sufficient in relation to my methodology.

Both organisations who took part were known to me as a social care professional. My organisation has good links with both and there have been instances of shared working between us. I have also been involved in some contact work for one of the organisations. Both were considered by myself and my organisation as having sound values and ethics and were considered 'good' social care providers. I would have expected staff within these organisations to have sound values, be person-centred and encourage and champion individual's rights and relationships. Therefore, I was unsurprised that overall all participants were encouraged to engage in relationships in the organisations I was in contact with and that staff supported them regarding this. It would have been beneficial to have recruited more participants from a diverse range of organisations which were less well known to me and to explore if staff attitudes and values varied across organisations, along with any impact this might have had on partner selection and relationships.

### **8.3.2 Diversity of the sample**

Regarding the research design, it was possible that the gatekeeper from Provider 1 did not understand the inclusion criteria as all of the participants they suggested were those in a relationship and no single people who had had experience of a relationship were identified. Provider 2 did suggest two possible participants but they were rejected (see page 71). This was not raised with the gatekeeper but doing so could have widened the range of potential participants. This was a limitation of the research as it could have provided an account of the experiences of single people with a learning disability who were looking for love. A number of the participants had been in a relationship for many years and may not have recalled as fully what it was like to be a person looking for love. Single people would have perhaps provided an account of what they were looking for in a potential partner. Most participants in this research when asked this question described their current partner. This may have been to not cause offence to their partner as most were interviewed within their respective couples or it was too abstract a concept to imagine what they would look for if they were single. Interviewing couples appeared to increase communication as participants 'played off' each other and this appeared to make couples more relaxed. However, in hindsight, it would have been beneficial to have conducted one interview with participants individually so they had the opportunity to share and discuss their thoughts without their partner being present. This could have resulted in a deeper level of disclosure and the exploration of some topics their partner may have found difficult such as sexual issues or a previous partner. In future research involving couples over a period of time I would consider requesting an individual interview.

The narrative of this research and my participants was one of exclusion from families, education, employment and accommodation etc., so my fear was that, to some extent, I had re-created this exclusion within my research. People with learning disabilities who engaged in homosexual relationships were excluded from the research. This was a difficult decision and a concern that this could be seen as prejudiced and further excluding a marginalised group. It was felt by both me and my supervisory team that the topic of partner selection and love within homosexual relationships for people with learning disabilities was too large a topic to be included in this thesis. The barriers and challenges faced by this group of individuals would share some common themes with heterosexual relationships but would also be different. Individuals would have possibly experienced the double discrimination of being a person with a learning disability and homosexual, and access to potential partners would most likely have been more

challenging. It was felt that this is a definite area for further research and such individuals' experiences deserve exploration.

Participants had to meet a required level of communication (such as the ability to talk in sentence about abstract concepts such as love) to take part in the research and those that did were not excluded. This was deemed necessary when the research design was formulated as the use of a narrative approach such as Van Manen's requires a level of narrative skill. However, I do not think I had fully explored the other ways in which I could have included more participants such as those who used sign language or Makaton to communicate. While I am unable to understand this myself, I could have possibly identified an assistant to support me with this or explored other options such as the use of art as a tool to explore the relationships of those who lacked the required verbal skills. A further piece of research could be focused on the relationships of adults with more profound disabilities or communication issues. However, a different method and methodology would then be more appropriate and this was not possible within the remit of this research and my skills as a researcher when commencing this study.

### **8.3.3 Inclusion of staff**

The participants discussed how staff perceived their relationship and the support provided around this. Overall, the participants were positive regarding their staff but it would have been interesting to have included staff in the research and to have interviewed them separately. This could have given another dimension to the research, allowing an insight into staff's perception of relationships for people with learning disabilities. This could possibly have allowed for an exploration of whether staff attitudes had changed since research such as Wolfe (1997) and Kelly *et al.* (2009). However, it was not considered appropriate to include staff's views in this research as the purpose was to provide a space for people with learning disabilities to share their experiences and for these to be fully explored and valued. If staff were included this could have suggested that the views of individuals were not sufficient unless supported by staff's views. In conducting the literature review there appeared to have been more research conducted which had included staff on the topic of sex and relationships than people with learning disabilities, and historically those with learning disabilities have been largely excluded from research. Therefore, staff were not included. However, it would be interesting to conduct a piece of further research which could explore staff attitudes in relation to partner selection and its influence on relationships and compare

these findings with this research.

## **8.4 Recommendations for Policy and Practice**

This final Section examines how the findings from this research can be used to influence social care policy and practice in order to improve the lives of people with learning disabilities either looking for love or in relationships. The recommendations can be considered in relation to the modified version of Maslow's hierarchy (Figure 3), highlighting what can be done by support providers, commissioners, social workers, parents/carers, teachers or policy makers to help people with learning disabilities to ascend the various levels.

### **8.4.1 Basic Physiological Needs: Finding love**

Despite advances in community integration my findings suggest that people with learning disabilities remain vulnerable to isolation and more needs to be done to combat this and to build relationships. Isolation reduces an individual's opportunity to meet a partner and form a relationship, therefore limiting their ability to fulfil their 'basic needs' of love and affection. Possible suggestions to reduce isolation are discussed below.

#### **Social Opportunities**

Support providers have a responsibility to help people become more included and in many cases are obliged to do this through the contracts held with commissioners. Research has shown that many people with learning disabilities are isolated and have small social circles. As a result, their staff are often very important to them and are seen more like friends. It could be possible to utilise their staff's own existing social networks as an opportunity to engage people in a wider range of diverse activities and possibly widen their social circle. Due to the 'risk adverse culture' within social care and an increased focus on safeguarding, some support providers may believe this is prohibited, but there is no law or CQC regulation surrounding this.

Utilising staffs' social networks would require provider organisations and social workers to have a more innovative and open view regarding how social care is provided, requiring individuals to use their professional judgement to determine if this was in a person's best interests and well planned. All of those involved would engage in an open

and honest discussion and reasonable lengths to keep their client's safe. Providers must be vigilant and make sure those they provide for are safe, but this fear must not be used to deny companionship. Providers need to help support staff to think through how to support people live fulfilling lives that include new and different ways to make friends.

### **Inclusive Activities**

Social care providers could do more to enable people to engage with their local community. Providers need to consider how to use activities that can specifically increase social opportunities (if this is what people desire) such as joining a swimming club instead of going swimming with staff, or joining a specialist interest group such as a knitting circle rather than knitting at home. Providers also need to remember the importance of maintaining pre-existing relationships that can be lost over time. Supporting people into employment has also been demonstrated to widen social circles. Widening a social circle does not necessarily mean people will find love but it increases the likelihood by increasing the number of people they have in their lives.

### **Accommodation**

Social workers and staff need to consider the compatibility of people when a vacancy becomes available in a supported living service or a registered care home as relationships for people with learning disabilities can develop here. Residents should be actively involved in selecting who moves into their home and, although this should be taking place as standard, there may be instances where this is not happening. There needs to be more consideration to ensure that people are compatible and, if desired, they can engage in meaningful conversation and activities. Also, adequate support should be provided to individuals who move into their own flats to help them adjust to living more independently, making links to their local community and keeping in contact with those they previously lived with if desired. More consideration should be given to ensuring that an individual's social networks are maintained when a person moves into a new property as often a person's support and housing needs are prioritised over their social needs. Consideration needs to be given to existing social circles including friends and family and maintaining links.

## **8.4.2 Safety and Security Needs: Safeguarding**

High-profile abuse cases, such as Winterbourne View (Flynn, 2012) demonstrate that



not every person with a learning disability has their 'safety and security needs' met in a way that allows them to ascend the modified version of Maslow's hierarchy (Figure 3). However, cases such as Winterbourne View perpetuate a climate of 'protectionism' and 'risk aversion' towards people with learning disabilities. My research shows that people still experience restrictions which may appear subtle but possibly reflect this. However, due to the reality of some peoples' learning disability, the involvement of staff within relationships remains essential. Any restrictions that take place, such as restricting a person who lacks the capacity to decide whether to engage in a sexual relationship, should be done 'in a person's best interests'. However, in some instances there needs to be a more balanced professional approach to safeguarding, where decisions are based on facts rather than staff's own views. While staff must consider individuals' 'safety and security needs', it is important that these needs are not prioritised at the expense of their client's 'love and belonging needs' unless it has been assessed that they lack the capacity to decide for themselves. The Mental Capacity Act 2005 enshrines in law the right to make our own decisions so more needs to be done to ensure that organisations act within the law and that restrictions are not placed on individuals who have the capacity to make their own choices. This requires better staff training and more professional attitudes. People with learning disabilities will not have true autonomy until they are treated and respected as adults and decisions are based on facts rather than the opinions and personal views of those involved in their care.

#### **8.4.3 Love and Belonging Needs: Physical Relationships**

Sex was not considered a 'basic need' in the modified version of Maslow's Hierarchy (Figure 3), however affection was included as a 'basic need'. My findings suggested that any form of physical contact (such as kissing) was a facilitator to relationships. Providing better support around sex and physical relationships could assist couples in ascending the hierarchy and help them to develop/maintain relationships.

##### **In Schools**

As a nation, the UK may appear to be less sexually-liberal than some of its European counterparts. This was evidenced in the lack of sexual assistants common in Germany, Holland and Denmark, who enable disabled people to have sex and enjoy intimate contact, and subsidised sexual relations as funded by the government in Holland. Until the UK becomes tolerant and liberal to such concepts it is unlikely we will become open enough to support people with disabilities in this way. It is understandable that this

openness will be even more problematic when considering something as taboo as sex for people with learning disabilities with all the complexities surrounding consent and capacity. This is a difficult, sensitive issue with no obvious solution. However, a more liberal form of sexual education for children could be a start to changing attitudes towards sex.

Under the Education Act 1996 it is mandatory that all UK primary and secondary students are provided with sex education which includes 'the biological aspects of puberty, reproduction and the spread of viruses and infection' (Sex Education Forum, 2011, p.1). The Sex and Relationship Education (SRE) includes teaching surrounding the emotional aspects of sex and relationships but is non-compulsory, although it is recommended that schools teach it. In 2007, a UK poll stated that 61% of boys and 70% of girls reported not having any information about personal relationships at school (UK Youth Parliament, 2007) and all of the respondents felt this information should be provided before the age of thirteen. SRE should be compulsory in UK schools, including schools for people with learning disabilities, and taught by professionals with specialist training. Education should enable young people to understand relationships, the responsibility each person has to a partner, respect, the ability to enjoy sexual and emotional relationships, provide them with sufficient skills to resist pressure, have a sense of their own rights and contraception (Sex Education Forum, 2003). If this type of education was provided to children at an earlier age, this may facilitate a less repressed/uninformed attitude within UK society. More emphasis on loving relationships for people with learning disabilities will hopefully raise this group's expectations about what they want in life and possibly lessen the amount of sexual abuse some women with learning disabilities experience.

### **For adults**

There was no discussion within the literature of sexual activities other than penetrative sex, suggesting that people with learning disabilities may not be fully aware of other ways they could enjoy a more physical relationship and increase intimacy with a partner. This highlights a possible need for sessions for adults with learning difficulties that focus on sexual issues beyond biology and contraception such as the emotional aspects of sex, sexual activities/enjoyment beyond penetration for both men and women and this could be provided either for couples or for single sex groups. More needs to be done to highlight the work done by sexual therapists (from organisations such as Relate) who work with adults with learning disabilities so that staff are aware of

the types of support available.

#### **8.4.5 Self Esteem Needs: Autonomy and Socially Valued Roles**

Figure 3 highlights how being in a relationship can increase autonomy for people with learning disabilities, as this provides the opportunity for them to be seen by society in the socially valued role of spouse/partner and this could possibly fulfil their 'self-esteem needs'. Despite the advances made towards increasing inclusion and rights for people with learning disabilities (see Section 2.2 and Chapter 6), a deeply-embedded culture of infantilisation persists. More needs to be done to portray people with learning disabilities in a positive light within the mainstream media, depicting them as autonomous adults in socially valued, respected and confident roles rather than portraying them as childlike or victims or omitting them completely. The role of a parent is valued in society but this is a role few people with learning disabilities experience.

McConnell *et al.* (2008) identified no correlation between IQ and parenting ability, but people with learning disabilities continue to face discrimination and barriers in relation to parenthood. There is a fear of people with learning disabilities having children, which relates back to concepts raised by the eugenics movement (see Chapter 6), as well as the cost implications for a struggling social care system. Professionals may claim to support parenthood for people with learning disabilities, and this is supported in law by legislation (such as the Human Rights Act, 1998) but prejudices still exist. This was possibly evidenced in staff's insistence on fitting a participant with a contraceptive implant before she successfully engaged in intercourse (Section 5.2.2).

People with learning disabilities should not hold the view that they should be excluded basic human right to family life. However, changes are required across professions to improve positive outcomes surrounding parenthood for people with learning disabilities. Discrimination towards disabled parents within the legal system and within social care needs to be addressed. Parents need to feel confident they will be treated fairly by people who understand their particular issues and that social services will be supportive of the pregnancy, remaining unprejudiced towards the capacity of the parents unless proven otherwise. Tarleton *et al.* (2006) highlighted how the use of a specialist advocate who understood the parents and the legal system could improve outcomes for in child protection procedures. This input should be available to all parents with learning disabilities.

There also needs to be more specialist support services for families that work with parents both before and after a birth in order to ensure the best outcome for the family. Practical training for parents has shown to be beneficial (Feldman, 1994) and should be offered to all, both prenatally and postnatally (McConnell and Llewellyn, 2005). Social support was found to improve positive outcomes for families (Stenfert Kroese *et al*, 2002) and therefore more needs to be done to improve such opportunities, possibly by forming links with other new parents, both with and without learning disabilities. Further discussion on reducing isolation is discussed in 8.4.4. The English Good Practice Guidance on Working with Parents with a Learning Disability (DoH, 2007) stated that support to parents should be long-term to maximise success, including support when children reach school age and puberty (Pixa-Kettner, 2008). Children's social workers should also receive mandatory training regarding parents with a learning disability and consult specialist learning disability colleagues' advice for support and guidance when required.

There needs to be more positive role models in the mainstream media showing people with learning disabilities as married partners and/or parents. Social care providers could showcase more good practice to demonstrate that, with good support, this could be a possibility for more adults with learning disabilities. This would challenge society's perception and possibly raise expectations for people with learning disabilities to aspire to parenthood if this is what they wanted.

## **8.5 Dissemination**

I plan to feed back the main findings and recommendations of the research to my participants by producing a short document in an accessible format which will be sent to them directly.

I aim to publish various peer-review journal articles based on my findings. The first article will present the new and original finding of my research regarding what people with a learning disability look for in a potential partner and what the barriers and facilitators to forming relationships are for this group, within the context of attachment theory and Maslow's theory. Subsequently, I plan to publish an article evidencing how I applied Van Manen's methodology to people with learning disabilities as, to my knowledge, this was its first application to this client group. The process I undertook could be beneficial to other researchers planning to interview individuals and couples

with a learning disability. I aim to publish aspects of Chapter 6 which discussed relationships for people with learning disabilities in the political and cultural context of different eras as this is an original finding.

I intend to publish a number of shorter articles in the trade press, including Learning Disability Today and possibly Guardian Society which would reach a wide range of professionals in my field. Along with the main findings of my research relating to partner selection, I would also like to publish other findings regarding issues for people with learning disabilities such as a lack of expectation for parenthood and a sexual relationship; the influence of staff on relationships; the limited use of technology and the continuing isolation for many people with a learning disability. I plan to present my research at a conference within the learning disability/ social care sector. This could include the Housing and Support Alliance Conference, Paradigm and Learning Disability Today. This would reach a diverse range of delegates including people with learning disabilities, their staff and senior managers.

## **8.6 Concluding Reflections**

An interpretive hermeneutic phenomenological approach (Van Manen, 1990) enabled me via a series of interviews to gain an understanding of what people with learning disabilities desire in a potential partner and how their choices impact on the relationships they experience. The desire for a warm, loving and considerate partner, combined with the 'basic need' for companionship, was valued by all. Desired characteristics of partners and expectations for the relationship were rooted in a shared history and culture, with older people having lower expectations. People with learning disabilities were able to develop and maintain emotionally significant relationships that they valued highly, despite having to overcome significant adversity such as abuse, restrictions from family and staff, social isolation and neglect. Rather than acting as a barrier, staff mostly played a vital role in the development and maintenance of relationships, especially for people with higher support needs.

The most significant finding of my research is that participants, people who had experienced a range of life challenges not least with the embodied reality of their learning disability, wanted and had succeeded in finding someone to love and be loved by. Recognising this as a basic need is the first step to ensuring that everyone involved in supporting people with learning disabilities will facilitate this wherever possible.

## Reference List

- Abberley, P. (1987) The concept of oppression and the development of a social theory of disability, *Disability, Handicap and Society*, 2 (1), pp. 5-19.
- Abraham, J., Cooper, M. and Ferris, G. (2010) Spending time and money: memories of life in St. Lawrences, *British Journal of Learning Disabilities*, 38 (2), pp. 95-96.
- Ahern, A. L., Bennett, K. M., Kelly, M. and Hetherington, M. M. (2010) A qualitative exploration of young women's attitudes towards the thin ideal, *Journal of Health Psychology*, 16 (1), pp. 70-79.
- Aho, K. A. (2010) *Heidegger's Neglect of the Body*. Albany: University of New York.
- Ainsworth, M. D. S., Blehar, M.C., Waters, E. and Walls, S. (1978) *Patterns of attachment*. New York: Erlbaum.
- Ainsworth, M.D.S. and Wittig, B. A. (1969) Attachment and exploratory behaviour of one-year-olds in a strange situation, In: Foss, B.M. (ed.) *Determinants of infant behaviour: IV*. London: Methuen, pp. 111-136.
- Akerlof, G., Yellen, J. and Katz, M. (1996) An analysis of out-of-wedlock childbearing in the united states, *Quarterly Journal of Economics*, 111 (2), pp. 277-317.
- Alaszewski, A. and Nio- Ong, B. (1990) *Normalisation in practice*. London: Routledge.
- Allen, D. G. (1995) Hermeneutics: philosophical traditions and nursing practice research, *Nursing Science Quarterly*, 8 (4), pp. 174-182.
- Allen, E. S., Atkins, D. C., Baucom, D. H., Snyder, D. K., Gordon, K. C., and Glass, S. P. (2005) Intrapersonal, interpersonal, and contextual factors in engaging in and responding to extramarital involvement, *Clinical Psychology: Science and Practice*, 12 (2), pp. 101-130.

Amato, P. R. and Previti, D. (2003) Reasons for divorcing: Gender, social class, the life course and adjustment, *Journal of Family Issues*, 24 (5), pp. 602-626.

Anderson, D. W. (2004) *Human rights and persons with disabilities in developing nations of Africa*. Birmingham: Stamford University.

Anderson, P. and Kitchin, R. (2000) Disability, space and sexuality: access to family planning services, *Social Science and Medicine*, 51 (8), pp. 1163-1173.

Andrinopoulos, K., Kerrigan, D. and Ellen, J. M. (2006) Understanding sex partner selection from the perspective of inner-city black adolescents, *Perspective Sex Reproductive Health*, 38 (3), pp. 132-8.

Armour, M., Rivaux, S. L. and Bell, H. (2009) Using context to build rigor: application to two hermeneutic phenomenological studies, *Qualitative Social Work*, 8 (1), pp. 101-122.

Association for Supported Living (2011) *There is an alternative*. Available from: [http://www.challengingbehaviour.org.uk/learning-disability-files/ASLAlternative\[1\].pdf](http://www.challengingbehaviour.org.uk/learning-disability-files/ASLAlternative[1].pdf) [Accessed 15<sup>th</sup> March 2013].

AVERT, no date. *Homophobia*. Available from: <http://www.avert.org/homophobia.htm> [Accessed 13th September 2014].

Avery, L. and Lazdane, G. (2008) What do we know about sexual and reproductive health of adolescents in Europe?, *European Journal of Contraception and Reproductive Health Care*, 13 (1), pp. 58-70.

Bane, G., Flaherty, J., Mahon, A., McDonagh, P., Wolfe, M., Deely, M., Hopkins, R., Minogue, G., Curry, M., Donohoe, B., Tierney, E., E, G., Iriarte, O' Doherty, S. and Shannon, S. (2012) Relationships of people with learning disabilities in Ireland, *British Journal of Learning Disabilities*, 40 (2), pp. 109-122.

Bank-Mikkelsen, N. (1980). Denmark, in: Flynn, R.J. and Nitsch, K. (eds.) *Normalisation, social integration and community services*. Baltimore, MD: University Park Press, pp. 51-70.

Barber, C. (2012) Learning disability: 175 years of legislation and reports, *British Journal of Healthcare Assistants*, 6 (4), pp. 190-194.

Barker, D. (1983) How to curb the fertility of the unfit: the feeble-minded in Edwardian Britain, *Oxford Review of Education*, 9 (3), pp. 197-211.

Baron-Cohen, S., Leslie, A. M. and Frith, U. (1985) Does the autistic child have a "theory of mind"?, *Cognitions*, 21 (1), pp. 37-46.

Barthes, R. (1986) *The rustle of language*. New York: Hill and Wang.

Bates, P. and Davis, F. A. (2004) Social capital, social inclusion and services for people with learning Disabilities, *Disability and Society*, 19 (3), pp. 195-207.

Baxter, C., Poonia, K., Ward, L., Nadirshaw, Z. and Martin, A. (1990) *Double discrimination: issues and services for people with learning disabilities from black and ethnic minority communities*. London: King's Fund Centre.

BBC (2005) *The 1980s AIDS campaign*. Available from: <http://news.bbc.co.uk/1/hi/programmes/panorama/4348096.stm> [Accessed 20th September 2014].

BBC (2010) *Five key moments in Britain's sexual revolution*. Available from: <http://news.bbc.co.uk/1/hi/magazine/8456543.stm> [Accessed 20th September 2014].

Beart, J. (2005) 'I won't think of meself as a learning disability. But I have': social identity and self-advocacy, *British Journal of Learning Disabilities*, 33 (3), pp. 128–131.

Benefits and Work (2013). Personal Independence Payment (PIP). Available from: <http://www.benefitsandwork.co.uk/personal-independence-payment-pip> [Accessed 24th August 2013].

Bennhold, K. (2010) *In Sweden, men can have it all*. The New York Times. Available form: <http://www.nytimes.com/2010/06/10/world/europe/10iht-sweden.html?pagewanted=all&r=0> [Accessed on 19<sup>th</sup> July 2013].



Berscheid, E. and Hatfield, W. E. (1978) *Interpersonal attraction (2nd ed.)*. Reading MA: Addison-Wesley.

Bewley, T. (2008) *Madness to mental illness. A history of the royal college of psychiatrists*. London: Royal Collage of Psychiatrists.

Binet, A. and Simon, T. (1916) *The development of intelligence in children: The Binet-Simon Scale*. Vineland NJ: Williams and Wilkins.

Blanchflower D.G. and Oswald, A. J. (2004) Money, sex and happiness: An empirical study, *Scandinavian Journal of Economics*, 106 (3), pp. 393-415.

Blinder, S. (2011) *UK public opinion toward immigration: Overall attitudes and level of concern*. Available from: [www.migrationobservatory.ox.ac.uk/briefings/uk-public-opinion-toward-immigration-overall-attitudes-and-level-concern](http://www.migrationobservatory.ox.ac.uk/briefings/uk-public-opinion-toward-immigration-overall-attitudes-and-level-concern) [Accessed 23rd September 2014].

Bloom, T. and Tonkiss, K. (2013) European union and commonwealth free movement: A historical-comparative perspective, *Journal of Ethnic and Migration Studies*, 39 (7), pp. 1067-1085.

Bogaert, A. F. and Sadava, S. (2002) Adult attachment and sexual behavior, *Personal Relationships*, 9 (2), pp. 191–204.

Booth, T. (2000) Parents with learning difficulties, child protection and the courts, *Representing Children*, 13 (3), pp.175-188.

Booth, T. and Booth, W. (1998) *Advocacy for parents with learning difficulties: developing advocacy support*. York: Joseph Rowntree Foundation.

Booth, T. and Booth, W. (2003) Self advocacy and supported learning for mothers with learning difficulties, *Journal of Intellectual Disabilities*, 7 (2), pp.165-193.

Booth, T., Booth, W. and McConnell, D. (2005) The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts, *Journal of Intellectual Disability Research*, 18 (1), pp. 7-17.

Booth, W. (1998) Doing research with lonely people, *British Journal of Learning Disabilities*, 26 (4), pp. 132–134.

Bowlby, J. (1944) Forty-four juvenile thieves: Their character and home-life. *International Journal of Psychoanalysis*, 25 (1), pp. 19-52.

Bowlby, J. (1951) Maternal care and mental health, *Bulletin of the World Health Organisation*, 3 (3), pp. 355-534.

Bowlby, J. (1966) *Maternal care and mental health and deprivation of maternal care*. New York: Shocken Books.

Bowlby, J. (1969) Attachment and loss (Volume 1) *attachment*. London: Hogarth.

Bowlby, J. (1973) Attachment and loss (Volume 2) *separation*. London: Hogarth.

Bowlby, J. (1979) *The making and breaking of affectional bonds*. London: Routledge.

Bowlby, J. (1980) *Attachment and loss (Volume 3) loss, sadness and depression*. London: Hogarth.

Brend, M. (2008) *First and last*. London: Choice Support Press.

Brennan, K. A., Wu, S. and Love, J. (1998) Adult romantic attachment and individual differences in attitudes toward physical contact in the context of adult romantic relationships, in: Simpson, J. and Rholes, W. S. (eds.) *Attachment theory and close relationships*. New York: Guilford Press.

Brignell, V. (2010) *The eugenics movement Britain wants to forget*. NewStatesman. Available from: <http://www.newstatesman.com/society/2010/12/british-eugenics-disabled> [Accessed 6th April 2013].

Bristol University (2008) *Facts and figures about parents with learning disabilities in England*. Available from: <http://www.bristol.ac.uk/wtwpn/resources/facts-pwld.pdf> [Accessed 24th August 2013].

British Psychological Society (2000) *Learning disability: Definitions and contexts*. Leicester: British Psychological Society.

Brown, A. and Finkelhar, D. (1986) Impact of child sexual abuse: A review of the research, *Psychological Bulletin*, 99 (1), pp. 66-77.

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 (2), pp. 123-142.

Brown, G. and Harris, T. (1989) *Life events and illness*. New York: Guilford Press.

Browne, K. (2009) *The risk to children in institutional care*. London: Save the Children.

Brugha, T., Cooper, S.A., McManus, S., Purdon, S., Smith, J., Scott, F.J., Spiers, N. and Tyrer, F. (2012) *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 adult psychiatric morbidity survey*. Available from: <http://www.hscic.gov.uk/catalogue/PUB05061/esti-prev-auti-ext-07-psyc-morb-surv-rep.pdf> [Accessed 10th September 2014].

Buck vs. Bell (1927) 274 U.S. 200.

Buss, D. M. (1994) *The evolution of desire: Strategies of human mating*. New York: Basic Books.

Buss, D. M. and Barnes, M. (1986) Preferences in human mate selection, *Journal of Personality and Social Psychology*, 50 (3), pp. 559-570.

Butterworth, J., Smith, F. A., Cohen Hall, A., Migliore, A., Winsor, J., Domin, D. and Timmons, J. C. (2011) *The national report on employment services and outcomes*. Boston: Institute for Community Inclusion (UCEDD).

Buunk, B. P. and Schaufeli, W. B. (1999) Reciprocity in Interpersonal relationships: an evolutionary perspective on its importance for health and well-being, *European Review of Social Psychology*, 10 (1), pp. 259-291.

Cienci, R. and Gambrel, P. A. (2003). Maslow's hierarchy of needs: Does it apply in a collectivist culture, *Journal of Applied Management and Entrepreneurship*, 8 (2), pp. 143–161.

Campaign for a Fair Society (2012). *Manifesto for a fair society 2012*. London: Centre for Welfare Reform.

Cangiano, A. and Shutes, I. (2010) Ageing, demand for care and the role of migrant care workers in the UK, *Journal of Population Ageing*, 3 (1-2), pp. 39-57.

Cangiano, A., I, Shutes., Spencer, S. and G. Leeson (2009). *Migrant Care Workers in Ageing Societies: Research Finding in the UK*. Oxford: Oxford University Centre on Migration, Policy and Society.

Care Quality Commission (2010) *Essential standards for quality and safety*. Available from: [http://www.cqc.org.uk/sites/default/files/documents/qac - dec 2011 update.pdf](http://www.cqc.org.uk/sites/default/files/documents/qac_-_dec_2011_update.pdf) [Accessed 8th May 2014].

Care Quality Commission (2014) *3 Lives: What have we learned, what we need to do*. Available from: <https://admin.cqc.org.uk/sites/default/files/2014%2006%2017%20Three%20Lives%20report%20FINAL.pdf> [Accessed 3<sup>rd</sup> December 2014].

Carroll, P. (2007) *Assessing the damage. The demographic impact on society and consequences for the health of women of the 1967 Abortion Act over 40 years*. Available from: <http://www.mededtrust.org.uk/files/40yearsimpact1967Abortion.pdf> [Accessed 21st September 2014].

Chapman, M., Iddon, P., Atkinson, K., Brodie, C., Mitchell, D., Parvin, G. and Willis, S. (2011) The misdiagnosis of epilepsy in people with intellectual disabilities: A systematic review, *Seizure*, 20 (2), pp. 101–106.

Chapman R. and McNulty, N. (2004) Building bridges? The role of research support in self-advocacy. *British Journal of Learning Disabilities*, 32 (2), pp. 77-85.

Chappell, L. (1992) Towards a sociological critique of the normalisation principle, *Disability, Handicap and Society*, 7 (1), pp. 35-53.

Chappell, A. L., Goodley, D. and Lawthom, R. (2001) Making connections: the relevance of the social model of disability for people with learning difficulties, *British Journal of Learning Disabilities*, 29 (2), pp. 45–50.

Chun, H. and I. Lee (2001) “Why do married men earn more: Productivity or marriage selection?”, *Economic Inquiry*, 39 (1), pp. 7-19.

Citizens Advice (no date) *Help for people on a low income - Income Support*. Available from:

[http://www.adviceguide.org.uk/england/benefits\\_e/benefits\\_help\\_if\\_on\\_a\\_low\\_income\\_ew/help\\_for\\_people\\_on\\_a\\_low\\_income\\_-\\_income\\_support.htm](http://www.adviceguide.org.uk/england/benefits_e/benefits_help_if_on_a_low_income_ew/help_for_people_on_a_low_income_-_income_support.htm) [Accessed 23<sup>rd</sup> August 2013].

Claessens, S. and Kose, A. M. (2012) *Recession: When bad times prevail*. Available from: <http://www.imf.org/external/pubs/ft/fandd/basics/recess.htm> [Accessed 23<sup>rd</sup> August 2013].

Clausen, J. (1995) *American Lives: Looking back at the children of the great Depression*. California: University of California Press.

Collins, N. L. and Read, S. J. (1990). Adult attachment, working models, and relationship quality in dating couples, *Journal of Personality and Social Psychology*, 58 (4), pp. 644-663.

Comfort, A. (1972) *The joy of sex: a gourmet guide*. New York: Simon and Schuster.

Commission for Social Care Inspection (2005) *The state of social care in England 2004-05*. London: CSCI.

Community Care (2007) *Learning difficulties residential home scandals: the inside story and lessons from Longcare and Cornwall*. Available from:

<http://www.communitycare.co.uk/articles/11/01/2007/102711/learning-difficulties->

residential-home-scandals-the-inside-story-and-lessons-from-longcare-and.htm  
[Accessed 17<sup>th</sup> August 2013].

Cook, L. B. and Sinason, V. (1998) Abuse of people with learning disabilities and other vulnerable adults, *Advances in Psychiatric Treatment*. 4 (2), pp. 119-125.

Cooper, S-A., Smiley, E., Morrison, J., Williamson, A. and Allan, L. (2007) Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors, *British Journal of Psychiatry*, 190 (1), pp. 27–35.

Craft, A. and Craft, M. (1979) *Handicapped married couples*. London: Routledge.

Creswell, J. W. (1998) *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: SAGE Publications LTD.

Cullen, D. and Gotell, L. (2002) From orgasms to organisations: Maslow, women's sexuality, and the gendered foundations of the needs hierarchy, *Gender, Work and Organisations*, 9 (5), pp. 537-555.

Cuskelly, M. and Bryde, R. (2004) Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample, *Journal of Intellectual Developmental Disability*, 29 (3), pp. 255–64.

Dahlberg, K., Drew, N. and Maria, N. (2001) *Reflective lifeworld research*. Lund: Studentlitteratur AB.

Darwin, C. (1859) *On the origin of species by means of natural selection, or the preservation of favoured races in the struggle for life*. London: John Murray.

Davis, S. (2013) *Grant scheme should pay for prostitute visits*, Worcester News. Available from:

[http://www.worcesternews.co.uk/news/10134381.Give\\_disabled\\_people\\_cash\\_for\\_call\\_girls/?ref=twtrrec](http://www.worcesternews.co.uk/news/10134381.Give_disabled_people_cash_for_call_girls/?ref=twtrrec) [Accessed 9<sup>th</sup> September 2013].

Department for Work and Pensions (2008) *Medical guidance for DLA and AA decision makers (adult cases): staff guide*. Available from:

<http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions/learning-disability/classification-ld.shtml> [Accessed 8<sup>th</sup> March 2013].

Department Of Health (2001) *Valuing People: A new strategy for people with learning disabilities In The 21st Century*. London: The Stationery Office.

Department of Health (2007) *The English good practice guidance on working with parents with a learning disability*. Available from: <http://dera.ioe.ac.uk/6709/> [Accessed 10th September 2014].

Department of Health (2008) *Our health, our care, our say: a new direction for community services*. London: The Stationery Office.

Department of Health (2009) *Valuing People Now- a new three-year strategy for people with learning disabilities*. London: The Stationery Office.

Department of Health (2009) *Valuing employment now- real jobs for people with learning disabilities*. London: The Stationery Office.

Department of Health (2009) *Safeguarding Adults: a consultation on the review of the 'No Secrets' guidance*. London: The Stationery Office.

Department of Health (2012) *Transforming care: A national response to Winterbourne View Hospital: Department of Health Review final report*. Available from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf) [Accessed 20 March 2014].

Department of Health and Social Security (1969) *Report of the committee of inquiry into allegations of ill treatment of patients and other irregularities at Ely Hospital, Cardiff*. London: The Stationery Office.

Department of Health and Social Security (1971) *Better services for the mentally handicapped*. London: The Stationery Office.

Department of Health and Social Security (1971) *Report of the Farleigh Hospital committee of inquiry*. London: The Stationery Office.

Department of Health and Social Security (1974) *Report of the South Ockendon Hospital committee of inquiry*. London: The Stationery Office.

Department of Health and Social Security (1978) *Report of the committee of inquiry into Normansfield Hospital*. London: The Stationery Office.

Department of Health and Social Security (1987) *Facilities and services of mental handicap hospitals and units in England*. Blackpool: Statistics and Research Division 2C (Fylde).

Department of Health and the Home Office (2000) *No Secrets- Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. London: The Stationery Office.

Dietch, J. (1978) Love, sex roles, and psychological health, *Journal of Personality Assessment*, 42 (6), pp. 626-634.

DiLillo, D. and Long, P. J. (1999) Perceptions of couple functioning among female survivors of child sexual abuse, *Journal of Child Sexual Abuse*, 7 (4), pp. 59-76.

Driving Up Quality Alliance (2013) *Driving up quality code*. Available from: <http://www.drivingupquality.org.uk/about-the-code> [Accessed 11th July 2014].

Duffy, S. (2006) The implications of individual budgets, *Journal of Integrated Care*, 14 (2), pp. 3–10.

Duncan, S. and Phillips, M. (2010) People who live apart together (LATs) – how different are they? *The Sociological Review*, 58 (1), pp. 112-134.

Dunn, J. (1988) *The beginnings of social understandings*. Oxford: Blackwell.

Dunn, J., Brown, J., and Beardsall, L. (1991) Family talk about feeling states and children's later understanding of others' emotions, *Developmental Psychology*, 27 (3), pp. 448–455.



Eckstein, D. and Goldman, A. (2001) The couple's gender-based communication questionnaire (CGCQ), *The Family Journal: Counseling and Therapy for Couples and Families*, 16 (1), pp. 83-86.

The Economist, (2011) *The flight from marriage*. The Economist. Available from: [http://www.economist.com/node/21526329#\\_r=1381509182674&count=horizontal&counturl=http%3A%2F%2Fwww.economist.com%2Fnode%2F21526329&id=twitter-widget&lang=en&original\\_referer=http%3A%2F%2Fwww.economist.com%2Fnode%2F21526329&related=theeconomist&size=mandtext=Asian%20demography%3A%20The%20flight%20from%20marriage%20%7C%20The%20Economist&url=http%3A%2F%2Fecon.st%2FKA1p77](http://www.economist.com/node/21526329#_r=1381509182674&count=horizontal&counturl=http%3A%2F%2Fwww.economist.com%2Fnode%2F21526329&id=twitter-widget&lang=en&original_referer=http%3A%2F%2Fwww.economist.com%2Fnode%2F21526329&related=theeconomist&size=mandtext=Asian%20demography%3A%20The%20flight%20from%20marriage%20%7C%20The%20Economist&url=http%3A%2F%2Fecon.st%2FKA1p77) [Accessed 11<sup>th</sup> October 2013].

Emerson, E. and Baines, S. (2011) *Health inequalities and people with learning disabilities in the UK: 2010*. Available from: [http://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_7479\\_IHaL2010-3HealthInequality2010.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf) [Accessed 26th September 2014].

Emerson, E. and Hatton, C. (2008) *People with learning disabilities in England*. Lancaster: Centre for Disability Research.

Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S., Christie, A. and Glover, G. (2012) *People with learning disabilities in England 2012*. Available from: <http://arcuk.org.uk/membersarea/wp-content/uploads/2013/08/IHAL-People-with-Learning-Disabilities-in-England-2012.pdf> [Accessed 10th May 2012].

Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S., Evison, F. and Glover, G. (2011) *People with learning disabilities in England 2011*. Available from: [http://www.improvinghealthandlives.org.uk/securefiles/141117\\_2041//IHAL2012-04PWLD2011.pdf](http://www.improvinghealthandlives.org.uk/securefiles/141117_2041//IHAL2012-04PWLD2011.pdf) [Accessed 10th May 2012].

Emerson, E., Malam, S., Davies, I. and Spencer, S. (2005) *Adults with learning disabilities in England 2003/04*. Lancaster: Centre for Disability Research.

Emerson, E. and McVilly, K. (2004) Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England, *Journal of Applied Research in Intellectual Disabilities*, 17 (3), pp. 191–197.

Family Planning Association (2008) *'It's my right'*. Available from:  
<http://www.fpa.org.uk/sexual-health-week/its-my-right> [Accessed 8<sup>th</sup> February 2013].

Feeney, J. A. and Noller, P. (1990) Attachment style as a predictor of adult romantic relationships, *Journal of Personality and Social Psychology*, 58 (2), pp. 281-291.

Feldman M. (1994) Parenting education for parents with intellectual disabilities: a review of outcome studies, *Research in Developmental Disabilities*, 15 (4), pp. 299–332.

Flagg, D. (2012) *Sexless marriage is surprisingly common*. Available from:  
<http://www.psychologytoday.com/blog/office-diaries/201203/sexless-marriage-is-surprisingly-common> [Accessed 22<sup>nd</sup> February 2013].

Flynn, M. (2012) *Winterbourne View Hospital: A serious case review*. South Gloucestershire Safeguarding Adults Board. Available from:  
<http://hosted.southglos.gov.uk/wv/report.pdf> [Accessed 22<sup>nd</sup> February 2013].

Foucault, M. (1980) *The history of sexuality, volume 1*. New York: Vintage Books.

Fowler, S. (2007) *The Workhouse: The People - The Places - The Life Behind Doors*. London: The National Archives.

Franz, C. E., McClelland, D. C., and Weinberger, J. (1991) Childhood antecedents of conventional social accomplishments in midlife adults: A 35-year prospective study, *Journal of Personality and Social Psychology*, 60 (4), pp. 586-595.

The Free Dictionary (no date) Available from:  
<http://www.thefreedictionary.com/random+sample> [Accessed 8th February 2013].

French, S. (2010) Cut-off: how we spent our time in a residential school, *British Journal of Learning Disabilities*, 38 (2), pp. 112-119.

French S., Swain J., Atkinson D. and Moore M. (2006). *An oral history of the education of visually impaired people: telling stories for inclusive futures*. Lampeter: The Edwin Mellen Press.

Futcher, S. (2011) Attitudes to sexuality of patients with learning disabilities: a review, *British Journal of Nursing*, 20 (1), pp. 8-14.

Fyson, R, (2009) Independence and Learning Disabilities: why we must also recognise vulnerability, *Journal of Integrated Care*, 17 (1), pp. 18-25.

Fyson, R. and Kitson, D. (2007) Independence or protection – does it have to be a choice? Reflections on the abuse of people with learning disabilities in Cornwall, *Critical Social Policy*, 27 (3), pp. 426-436.

Fyson, R., Tarleton, B. and Ward, L. (2007) *Support for Living? The impact of the Supporting People programme on housing and support for adults with learning disabilities*. Policy Press/Joseph Rowntree Foundation. Available from: <http://www.bristol.ac.uk/norahfry/research/completed-projects/support-findings.pdf> [Accessed 8th March 2013].

Gallup (2009) *What Alabamians and Iranians have in common*. Available from: <http://www.gallup.com/poll/114211/Alabamians-Iranians-Common.aspx> [Accessed 4th March 2013].

Galton, F. (1869) *Hereditary Genius*. London: Macmillan.

Garbarino, E and Strahilevitz, M. (2004) Gender differences in the perceived risk of buying online and the effects of receiving a site recommendation, *Journal of Business Research*, 57 (7), pp. 768–775.

Gardner, H. (1983) *Frames of mind*. New York: Basic Books.

Gates, B. and Waight, M. (2007) Reflections on conducting focus groups with people with learning disabilities: Theoretical and practical issues, *Journal of Research in Nursing*, 12 (2), pp. 111-126.

Ghail, M. (2000) The Irish in Britain: the invisibility of ethnicity and anti-Irish racism, *Journal of Ethnic and Migration Studies*, 26 (1), pp. 137-147.

Gilbert, T. (2009) From the workhouse to citizenship: four ages of learning disability, in: Jukes, M. (ed.) *Learning Disability Nursing Practice*. London: Quay Books, pp. 101-155.

Giorgi, A. (1985) *Phenomenology and psychological research*. Pittsburgh: Duquesne University.

Glaser, B. G. and Strauss, A.L. (1967) *The discovery of grounded theory: strategies for qualitative research*. Chicago: Aldine.

Goffman, E. (1961) *Asylums: essays on the social situation of mental patients and other inmates*. New York: Doubleday.

Goldin, C. and Katz, L. (2002) The power of the pill: oral contraceptives and women's career and marriage decisions. *Journal of Political Economy*, 110 (4), pp. 730–770.

Goodwin, R. (1990) Sex differences among partner preferences: Are the sexes really very similar?, *Sex Roles*, 23 (9-10), pp. 501-513.

Gould, S. and Dodd, K. (2014) 'Normal people can have a child but disability can't': the experiences of mothers with mild learning disabilities who have had their children removed, *British Journal of Learning Disabilities*, 42 (1), pp. 25–35.

Graham, J. M. (2011) Measuring love in romantic relationships: A meta-analysis, *Journal of Social and Personal Relationships*, 28 (6), pp. 748–771.

Grimmer, A. and Tribe, R. (2001) Counselling Psychologists' perceptions of the impact of mandatory personal therapy on development- an exploratory study, *Counselling Psychology Quarterly*, 14 (4), pp. 287-301.

Groce, N. E. (1997) Women with disabilities in the developing world, *Journal of Disability Policy Studies*, 8 (1-2), pp. 178-193.

Guest, G., Brunce, A. and Johnson, L. (2006) How many interviews are enough? An experiment with data saturation and variability, *Field Methods*, 18 (1), pp. 59-82.

Haavio-Mannila E., Roos, J. and Kontula, O. (1996) Repression, Revolution and Ambivalence: The Sexual Life of Three Generations, *Acta Sociologica*, 39 (4), pp. 409-430.

Hahn, H. (1990) The social component of sexuality and disability: Some problems and proposals, in: Nagler, M (ed.) *Perspectives on Disability*. Palo Alto: Health Markets Research, pp. 343-351.

Halifax, N. (2011) *The birth of the 'gay plague' myth*. Available from: <http://socialistworker.co.uk/art/24656/The+birth+of+the+%E2%80%98gay+plague%E2%80%99+myth> [Accessed 13th September 2014].

Ham, M., Jones, N., Mansell, I., Northway, R., Price, L., and Walker, G. (2004). 'I'm a researcher!' Working together to gain ethical approval for a participatory research study', *Journal of Learning Disabilities*, 8 (4), pp. 397-407.

Hardest Hit, (2012) *The tipping point: The human and economic costs of cutting disabled peoples support*. Available from: [http://www.sense.org.uk/sites/default/files/hardest\\_hit\\_tipping\\_point.pdf](http://www.sense.org.uk/sites/default/files/hardest_hit_tipping_point.pdf) [Accessed 10th January 2013].

Harlow, H. F. (1958) The nature of love, *American Psychologist*, 13, pp. 673-685.

Hart, W. D. (1996) Dualism, in: Guttenplan, S. (eds.) *A Companion to the Philosophy of Mind*. Oxford: Blackwell.

Hatfield, E., Pillemar, T., O'Brien, M. U. and Le, Y. L. (2008) The endurance of love: passionate and companionate love in newlywed and long-term marriages. *Interpersonal*, 2 (1), pp. 35-64.

Hawkes, G. (1995) Responsibility and Irresponsibility: young women and family planning, *Sociology*, 29 (2), pp. 257-73.

Hazan, C. and Shaver, P. R. (1987) Romantic love conceptualized as an attachment process, *Journal of Personality and Social Psychology*, 52 (3), pp. 511-524.

- Heidegger, M. (1978) *Being and time*. London: Wiley-Blackwell.
- Hendrick, S. S. and Hendrick, C. (1995) Gender differences and similarities in sex and love. *Personal Relationships*, 2 (1), pp. 55-65.
- Hill, C. E., Thompson, B. J. and Williams, E. N. (1997) A guide to conducting consensual qualitative research, *The Counselling Psychologist*, 25 (4), pp. 517-572.
- Hilton, E. and Henderson, L. (2003) Lived female experience of chronic bladder cancer: a phenomenological case study, *Urologic Nursing*, 23 (5), pp. 349–354.
- Hodges, J. and Tizard, B. (1989b) Social and family relationships of ex-institutional adolescents, *Journal of Child Psychology and Psychiatry*, 30 (1), pp. 77-97.
- Hofstede, G. (1980) *Culture's consequences: international differences in work-related values*. Beverly Hills, CA: SAGE Publications Ltd.
- Hollomotz, A. (2008) 'May we please have sex tonight?' – People with learning disabilities pursuing privacy in residential group settings, *British Journal of Learning Disabilities*, 37 (2), pp. 91–97.
- Holt, M. L., Devlin, J. M., Flamez, B. and Eckstein, D. (2009) Using the Holt Relationship Intimacy Questionnaire (HRIQ): What intimacy means to you and your partner, *The Family Journal*, 17 (2), pp.146-150.
- Home Office, Office for National Statistics and Ministry of Justice (2013) *An Overview of Hate Crime in England and Wales*. Available from:  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/266358/hate-crime-2013.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/266358/hate-crime-2013.pdf) [Accessed 28th September 2014]
- Howard, R. and Handy, S. (2004) 'The sterilisation of women with learning disabilities - some points for consideration', *The British Journal of Developmental Disabilities*, 50 (2), pp. 133– 141.
- Howe, D. (1995) *Attachment theory for social work practice*. Basingstoke: Palgrave Macmillan.

Hrdy, S.B. (2005) Comes the child before the man: How cooperative breeding and prolonged post weaning dependence shaped human potential, in: Hewlett, B. S. and Lamb, M.E. (eds.) *Hunter-Gatherer childhoods: Evolutionary, Developmental and Cultural Perspectives*. New Brunswick: Transaction Publishers, pp. 65-91.

Hreinsdottir, E.E. and Stefansdottir, G. (2010) Collaborative life history: different experiences of spending time in an institution in Iceland, *British Journal of Learning Disabilities*, 38 (2), pp. 103-109.

Hreinsdottir, E.E. and Stefansdottir, G., Lewthwaite, A., Ledger, S. and Shufflebotham, L. (2006) 'Is my story so different from yours'? Comparing life stories, experiences of institutionalization and self-advocacy in England and Iceland, *British Journal of Learning Disabilities*, 34 (3), pp. 157-166.

Hussein, S. (2010) Pay in adult social care in England, *Social Care Workforce Periodical Volume 6- May 2010*. London: Social Care Workforce Research Unit, King's College London.

Husserl, E. (1970) *The idea of phenomenology*. New York: Springer.

Impett, E. and Peplau, L. (2002) Why some women consent to unwanted sex with a dating partner: Insights from attachment theory, *Psychology of Women Quarterly*, 26 (4), pp. 360-370.

Jacobsen, T. and Hoffman, V. (1997) Children's attachment representations: Longitudinal relations to school behavior and academic competency in middle childhood and adolescence, *Developmental Psychology*, 33 (4), pp. 703-710.

Jamieson, L. (1999) Intimacy Transformed? A critical look at the 'Pure Relationship', *Sociology*, 33 (3), pp. 447-494.

Jay, P. (1979) *The Report of the committee of inquiry into mental handicap nursing and care*. London: Department of Health.

John, E. (2011) *Online dating: Computer says yes. But will we click?*, The Guardian. Available from: <http://www.guardian.co.uk/lifeandstyle/2011/jul/10/online-dating-will-we-click> [Accessed 8th February 2013].

Kelly, G., Crowley, H. and Hamilton, C. (2009) Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted', *British Journal of Learning Disabilities*, 37 (4), pp. 308–315.

Kempton, W. and Kahn, E. (1991) Sexuality and people with intellectual disabilities: A historical perspective, *Sexuality and Disability*, 9 (2), pp. 93-111.

Kenrick, D. (2010) *Rebuilding Maslow's pyramid on an evolutionary foundation. Psychology Today*. Available from: <http://www.psychologytoday.com/blog/sex-murder-and-the-meaning-life/201005/rebuilding-maslow-s-pyramid-evolutionary-foundation> [Accessed 8th August 2014].

Kent Parish Council, (no date) *Darenth Park Hospital*. Available from: <http://www.darenthpc.kentparishes.gov.uk/default.cfm?pid=4597> [Accessed 17<sup>th</sup> August 2013].

King, A. E. and Allen, T. T. (2009) Personal characteristics of the ideal African American marriage partner: A survey of adult black men and women, *Journal of Black Studies*, 39 (4), pp. 570-588.

Koritsas, S. and Iacono, T. (2012) Challenging behaviour and associated risk factors: An overview (Part I), *Advances in Mental Health and Intellectual Disabilities*, 6 (4), pp. 199–214.

Knestrict, T. (2002) *A post-modern critique of attachment theory: Moving towards a socially just ecological framework*. Cincinnati: University of Cincinnati.

Kobak, R. R., Cole, H. E., Ferenz-Gillies, R., Flemming, W. S. and Gamble, W. (1993) Attachment and emotional regulation during mother-teen problem-solving. A control theory analysis, *Child Development*, 64 (4), pp. 231-245.

Koffman, O. (2012) Children having children? Religion, psychology and the birth of the



teenage pregnancy problem, *History of the Human Sciences*, 25 (1), pp. 119-134.

Lacey, R. S., Reifman, A., Scott, J. P., Harris, S. M. and Fitzpatrick, J. (2004) Sexual-moral attitudes, love styles, and mate selection, *The Journal of Sex Research*, 41 (2), pp. 121-128.

Langdrige, D. (2007) *Phenomenological psychology: theory, research, and method*. New York: Pearson / Prentice Hall.

Larose, S. and Bernier, A. (2001) Social support processes: Mediators of attachment state of mind and adjustment in later late adolescence, *Attachment and Human Development*, 3 (1), pp. 96-120.

Layton-Henry, Z. (1985) *The New Commonwealth Migrants 1945-62*. Available from: <http://www.historytoday.com/zig-henry/new-commonwealth-migrants-1945-62> [Accessed 13th September 2014].

Learner, A. (2013) *Care home provider appoints sex 'champions'*, The Guardian. Available from: <http://www.guardian.co.uk/social-care-network/2013/mar/13/care-home-sex-champions> [Accessed 16th March 2013].

Lee J. A. (1973) *Colours of love: an exploration of the ways of loving*. Toronto: New Press.

Lerner, H. (1990) *The dance of intimacy*. New York: Harper and Row.

Lesseliers, J. (1999) 'A Right to Sexuality?', *British Journal of Learning disabilities*, 27 (4), pp. 137-140.

Levesque, L. M. and Caron, S. L. (2004) Dating preferences of women born between 1945 and 1960, *Journal of Family Issues*, 25 (6), pp. 883-846.

Levitt, H. M. (2006) How I ended up in a happy relationship: Women's process of successful partnering, *Journal of Humanistic Psychology*, 46 (4), pp. 449-473.

Lieberman, A. F. and Pawl, J. H. (1988) Clinical applications of attachment theory, in Belsky, I. and Nezworski, T. (eds.) *Clinical implications of attachment*. Hillsdale: NJ, Erlbaum, pp. 325–351.

Lindau, S. T., Schumm, P. L., Laumann, E. O., Levinson, W., O’Muirheartaigh, C.O. and Waite, L. J. (2007) A study of sexuality and health among older adults in the United States, *New England Journal of Medicine*, 357 (8), pp. 762-774.

Löfgren-Mårtenson, L. (2004) ‘May I?’ About sexuality and love in the new generation with intellectual disabilities, *Sexuality and Disability*, 22 (30), pp. 197-206.

Love, P. and Robinson, J. (1994) *Hot monogamy: Essential steps to more*. New York: Penguin.

Low Pay Commission (2010) *National minimum wage: Low pay commission report 2010*. London: Low Pay Commission.

Ly, R. (2009) Learning disabilities: able to love: people with learning disabilities face many barriers in getting sexual health advice and support, not least a reluctance to view them as sexual beings, *Community Practitioner*, July 2009.

Lynch, E. (2005) Sexual revolution, *Nursing Standard*, 20 (8), pp. 20-21.

Madison, G. B. (1988) *The hermeneutics of postmodernity: Figures and themes*. Indianapolis: Indiana University Press.

Mansell, J. (2010) Raising our sights: Services for adults with profound intellectual and multiple disabilities, *Tizard Learning Disability Review*, 15 (3), pp. 5-12.

Marazziti, D., Akiskal, H.S., Rossi, A. and Cassano, G. B. (1999) Alteration of the platelet serotonin transporter in romantic love, *Psychological Medicine*, 29 (3), pp. 741-745.

Marendaz, L. and Wood, K. (1999) The effects of childhood sexual abuse on female sexuality: A model of intervention, in: *Restoration for victims of crime conference convened by the Australian Institute of Criminology in conjunction with Victims Referral*

and Assistance Service, Melbourne, September 1999. Available from:  
[http://www.aic.gov.au/media\\_library/conferences/rvc/marendaz.pdf](http://www.aic.gov.au/media_library/conferences/rvc/marendaz.pdf) [Accessed 20  
March 2014].

Maslow, A. H. (1943) A theory of human motivation. *Psychological Review*, 50 (4), pp. 370-96.

Maslow, A. (1954) *Motivation and personality*. New York: Harper and Row.

Masuda, M. (2003) Meta-analyses of love scales: Do various love scales measure the same psychological constructs?, *Japanese Psychological Research*, 45 (1), pp. 25-37.

Mattinson, J. (1970) *Marriage and mental handicap*. London: Duckworth.

Mattinson, J. and Sinclair, I. (1979) *Mate and stalemate: Working with marital problems in a social services department*. Oxford: Blackwell.

Mayes, R., Llewellyn, G. and McConnell, D. (2006) Misconception: the experience of pregnancy for women with learning disabilities, *Scandinavian Journal of Disability Research*, 8 (2-3), pp. 120-131.

McCarthy, M. (1998) Interviewing people with learning disabilities about sensitive topics: A discussion of ethical issues, *British Journal of Learning Disabilities*, 26 (4), pp. 140-146.;

McCarthy, M. (1999) *Sexuality and women with learning disabilities*. London: Jessica Kingsley Publishers.

McCarthy, M. (2009) 'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities, *Women's Studies International Forum*, 32 (2009), pp. 198–208.

McConnell, D. and Llewellyn, G. (2000) Disability and discrimination in statutory child protection proceedings, *Disability and Society*, 15 (6), pp. 883-895.

McConnell, D. and Llewellyn, G. (2005) Social inequity, the deviant parent and child

protection practice, *Australian Journal of Social Issues*, 40 (4), pp. 553-556

McConnell, D., Mayes, R. and Llewellyn, G. (2008) Women with intellectual disability at risk of adverse pregnancy and birth outcomes, *Journal of Intellectual Disability Research*, 52 (6), pp. 529-535.

McLeod, J. (2001) *Qualitative research in counselling and psychotherapy*. London: SAGE Publications Ltd.

McLeod, S. A. (2008) *Hodges and Tizard study*. Available from: <http://www.simplypsychology.org/hodges-tizard.html> [Accessed 6th October 2013].

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R. and Burton-Smith, R.M. (2005) 'I Get by with a little help from my friends': Adults with intellectual disability discuss loneliness, *Journal of Applied Research in Intellectual Disabilities*, 19 (2), pp. 191–203.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R. and Burton-Smith, R.M. (2006). Self-advocates have the last say on friendship, *Disability and Society*, 21 (7), pp. 693–708.

Mehra, B (2002) *Bias in qualitative research: Voices from an online classroom*. Available from: <http://www.nova.edu/ssss/QR/QR7-1/mehra.html> [Accessed 17th October 2013].

Mencap (no date) *Timeline*. Available from: <http://www.mencap.org.uk/about-us/our-history/timeline> [Accessed 10th March 2013].

Mercer, J. (1973) *Labelling the mentally retarded: Clinical and social systems perspective on mental retardation*. Berkeley and London: University of California Press.

Mickel, A. (2008) *Personalisation exclusive: poll of social workers' views*. Available from: [Zttp://www.communitycare.co.uk/articles/22/10/2008/109761/personalisation-exclusive-poll-of-social-workers-views.htm](http://www.communitycare.co.uk/articles/22/10/2008/109761/personalisation-exclusive-poll-of-social-workers-views.htm) [Accessed 4<sup>th</sup> April 2013].

The Migration Observatory (2011) *Social care for older adults and the demand for migrant workers*. Available from: <http://migrationobservatory.ox.ac.uk/policy-primers/social-care-older-people-and-demand-migrant-workers>. [Accessed 4th April 2013].

- Mikulincer, M. (1998) Attachment working models and the sense of trust: An exploration of interaction goals and affect regulation, *Journal of Personality and Social Psychology*, 74 (5), pp. 1209-1224.
- Mirfin-Veitch, B., Bray, A., Williams, S., Clarkson, J. and Belton, A. (1999) Supporting parents with intellectual disabilities, *New Zealand Journal of Disability Studies*, 6 (2), pp. 60-74.
- Miyake K, Chen S-J, and Campos J. (1985) Infant temperament and mother's mode of interaction and attachment in Japan; an interim report, In: Bretherton, I and Waters, E. (eds.) *Growing points of attachment theory and research. Monographs of the Society for Research in Child Development*. Chicago: University of Chicago press.
- Mole, S. (2001) From empire to equality? Migration and the commonwealth, *Round Table*, 90 (358), pp. 89-93.
- Moran, D. (2000) *Introduction to phenomenology*. New York: Routledge.
- Morris, P. (1969) *Put away: A sociological study of institutions for the mentally retarded*. University of California: Routledge and Kegan Paul Limited.
- Morris, J (1998) *Still missing? Volume 1. The experience of disabled children and young people living away from their families*. London: The Who Cares? Trust.
- Morbidity and Mortality Weekly Report (1983) Current trends acquired immunodeficiency syndrome (AIDS) Update - United States, *Centers for Disease Control and Prevention*, 32 (24), pp. 309-11
- Moses, J. and Knutsen, T. (2007) *Ways of knowing. Competing methodologies in social and political research*. Palgrave: Macmillan.
- Moss, B. F. and Schwebel, A. I. (1993) Marriage and romantic relationships, *Family Relations*, 42 (1), pp. 31-37.

Mulhall, J., King, R., Glina, S. and Hvidsten, K. (2008) Importance of and satisfaction with sex among men and women worldwide: Results of the global better sex survey, *The Journal of Sexual Medicine*, 5 (4), pp. 788-795.

Mullen, P. E., Martin, L. M., Anderson, J. C., Romans, S. E. and Herbison, G.P. (1994) The effects of child sexual abuse on social, interpersonal and sexual function in adult life, *British Journal of Psychiatry*, 165 (1), pp. 35-47.

Mulveen, R. and Hepworth, J. (2006) An interpretative phenomenological analysis of participation in a pro-anorexia internet site and its relationship with disordered eating, *Journal of Health Psychology*, 11 (2), pp. 283–96.

Munday, D., Francome, C. and Savage, W. (1989) Twenty one years of legal abortion, *British Medical Journal*, 298 (6682), pp. 1231-1234.

Murray, A. J. and McKenzie, K. (2014) The accuracy of the Learning Disability Screening Questionnaire (LDSQ) in classifying severity of impairment: A brief report, *Journal of Intellectual and Developmental Disability*, 39 (4), pp. 370-374.

Natal 2 (1999-2001) The national survey of sexual attitudes and lifestyles. Available from:

[http://www.natsal.ac.uk/media/823260/natsal\\_findings\\_final.pdf?utm\\_source=2013%20Findingsandutm\\_medium=Downloadandutm\\_campaign=Infographic%20findings%202013](http://www.natsal.ac.uk/media/823260/natsal_findings_final.pdf?utm_source=2013%20Findingsandutm_medium=Downloadandutm_campaign=Infographic%20findings%202013) [Accessed 10th May 2013].

National Archives (no date) *Power, politics and protest. The growth of political rights in Britain in the 19<sup>th</sup> Century*. Available from:

<http://www.nationalarchives.gov.uk/education/politics/g1/background.htm> [Accessed 10th May 2013].

Netdoctor (2011) *Depo- Provera*. Available from: <http://www.netdoctor.co.uk/sex-and-relationships/medicines/depo-provera.html> [Accessed 19th July 2013].

Nirje, B. (1980) The normalization principle, in: Flynn, R. J. and Nitsch, K. E. (eds.) *Normalization, social integration and community services*. Baltimore: University Park Press.

Northway, R. (2000) Finding out together: lessons in participatory research for the learning disability nurse, *Mental Health Care*, 3 (7), pp. 229–232.

Nunkoosing, K and John, M. (1997) Friendships, relationships and the management of rejection and loneliness by people with learning disabilities, *Journal of Intellectual Disabilities*, 1 (1), pp. 10-18.

Oberman, M. (2010) Thirteen ways of looking at Buck v. Bell: Thoughts occasioned by Paul Lombardo's "Three Generations, No Imbeciles", *Journal of Legal Education*, 59 (3), pp. 357- 392.

O'Brien, J. (1989) *What's worth working for? Leadership for Better Quality Human Services*. Georgia: Responsive Systems Associates.

Ofcom (2012) *Adults media use and attitudes report*. Available from: <http://stakeholders.ofcom.org.uk/binaries/research/media-literacy/media-use-attitudes/adults-media-use-2012.pdf> [Accessed 11th February 2013].

Office for National Statistics (2010) *Live births in England and Wales by characteristics of mother 1, 2010*. Available from: <http://www.ons.gov.uk/ons/rel/vsob1/characteristics-of-Mother-1--england-and-wales/2010/stb-live-births-in-england-and-wales-by-characteristics-of-mother-2010.html> [Accessed 10th March 2013].

Office for National Statistics (2012) *Marriages in England and Wales, 2010*. Available from: <http://www.ons.gov.uk/ons/rel/vsob1/marriages-in-england-and-wales--provisional-/2010/marriages-in-england-and-wales--2010.html> [Accessed 20th May 2013].

Office for National Statistics (2013) *Births in England and Wales by Characteristics of Birth 2, 2011*. Available from: [http://www.ons.gov.uk/ons/dcp171778\\_298892.pdf](http://www.ons.gov.uk/ons/dcp171778_298892.pdf) [Accessed 20th September 2014].

Office for National Statistics (2014) *Net migration to the UK was 243,000 in the year ending March 2014, according to latest provisional estimates*. Available from: <http://www.ons.gov.uk/ons/rel/migration1/migration-statistics-quarterly-report/august-2014/sty-net-migration.html> [Accessed 20th September 2014].

Office of Population Censuses and Surveys (1981) *Mid-1980 estimates of the population of the new commonwealth and Pakistani ethnic origin*, Monitor PP1 81/6. London: OPCS.

O'Reilly, S., Knox, D. and Zusman, M. (2009) What college women want in a marriage partner, *Collage Students Journal*, 43 (2), pp. 503-506.

Otway, L. J. and Carnelley, K. B. (2013) Exploring the associations between adult attachment security and self-actualization and self-transcendence, *Self and Identity*, 12 (2), pp. 217–230.

Owens, J. (2015) Exploring the critiques of the social model of disability: the transformative possibility of Arendt's notion of power, *Sociology of Health and Illness*, 37 (3), pp. 385–403.

Owen, F. A., Griffiths, D. M., Feldman, M., Sales, C. and Richards, D. A. (2000). Perceptions of acceptable boundaries of persons with developmental disabilities and their care providers, *Journal on Developmental Disabilities*, 7 (1), pp. 34-49.

Patmore, C. (2003) *Understanding home care providers. Live issues about management, quality and relationships with Social Services Purchasers*. York: York Home Care Internet Publications.

Parchomiuk, M. (2013) Model of intellectual disability and the relationship of attitudes towards the sexuality of persons with an intellectual disability, *Sexuality and Disability*, 31 (2), pp. 125-139.

Park, A., Clery, E., Curtice, J., Phillips, M. and Utting, D. (2012) *British social attitudes: the 29th Report*. London: NatCen Social Research.

Parahoo, K. (1997) *Nursing research: Principles, process, issues*. London: Macmillan.

Paul, A., Cawson, P. and Paton, J. (2006) *Safeguarding disabled children in residential special schools*. London: NSPCC.

Péloquin, K., Brassard, A., Delisle, G. and Bédard, M. (2013) Integrating the



attachment, caregiving, and sexual systems into the understanding of sexual satisfaction, *Canadian Journal of Behavioral Science*, 45 (3), pp. 185-195.

People First (no date) *People First – Info and FAQ*. Available from:  
<http://peoplefirstltd.com/about-us/info-faq/> [Accessed 13th September 2014].

Lord Percy (1957) *Report of the royal commission on the law relating to mental illness and mental deficiency*. London: HMSO.

PewResearch (2014) *Global views on morality*. Available from:  
<http://www.pewglobal.org/2014/04/15/global-morality/table/premarital-sex/> [Accessed 26th September 2014].

Pitt, V. (2013) *Patients left in learning disability hospitals for years*. Available from:  
<http://www.communitycare.co.uk/static-pages/articles/patients-in-learning-disability-hospitals-stay-for-years/> [Accessed 4<sup>th</sup> April 2013].

Pixa-Kettner, U. (2008) Parenting with an intellectual disability in Germany: results of a nationwide study, *Journal of applied research in intellectual disability*, 21 (5), pp. 315-319.

Polkinghorne, D. (1983) *Methodology for the human sciences: Systems of inquiry*. Albany: State University of New York Press.

Porter, D. (1999) Eugenics and the sterilization debate in Sweden and Britain before World War II, *Scandinavian Journal of History*, 24 (2), pp. 145-162.

Purnell, D. (2008) *Sex and the search for intimacy*. Available from:  
<http://www.everystudent.com/features/search.html> [Accessed 22nd February 2013].

Quarmby, K. (2013) *Scapegoat: Why we are failing disabled people*. London: Portobello Books.

Race, D. (1995) Historical development of service provision, in: Malin, D. (ed.) *Services for People with Learning Disabilities*. London: Routledge, pp. 46-79.

Rasmussen, P. and Kilbourne, K. (2007) Sex in intimate relationships: Variations and challenges, in: Peluso, P (ed.) *Infidelity: A practitioner's guide for working with couples in crisis*. New York: Rutledge, pp. 11-31.

Reavey, P. and Gough, D. (2000) Dis/locating blame: survivors' constructions of self and sexual abuse, *Sexualities*, 3 (3), pp. 325–346.

Reed, S. J. (2000) Shame and hope in sexual addiction, *Journal of Ministry in Addiction and Recovery*, 7 (1), pp. 9-17.

Regan, P. C. (1998) What if you can't get what you want? Willingness to compromise ideal mate selection standards as a function of sex, mate value and relationship Context, *Personality and Social Psychology Bulletin*, 24 (12), pp. 1294-1303.

Regan, P. C. and Anupama, J. (2003) Ideal partner preferences among adolescents, *Social Behaviour and Personality: an international journal*, 31 (1), pp. 13-20.

Robertson-Malt, S. (1999) Listening to them and reading me: a hermeneutic approach to understanding the experience of illness, *Journal of Advanced Nursing*, 29 (2), pp. 290- 297.

Rodgers, C. (2009) (S)excerpts from a life told: Sex, gender and learning disability, *Sexualities*, 12 (3), pp. 270-288.

Rogge, R. D., Bradbury, T. N., Hahlweg, K., Engl, J. and Thurmaier, F. (2006) Predicting marital distress and dissolution: Refining the two-factor hypothesis, *Journal of Family Psychology*, 20 (1), pp. 156-159.

Royal College of Nursing (2011) *Older people in care homes: sex, sexuality and intimate relationships. An RCN discussion and guidance document for the nursing workforce*. London: The Royal College of Nursing.

Roy, M (2012) A case note follow-up of women with intellectual disability referred for sterilization, *Journal of Intellectual Disabilities*, 14 (1), pp. 43-52.

Russell, V., Baker, L. and McNulty, J. (2013) Attachment insecurity and infidelity in marriage: Do studies of dating relationships really inform us about marriage?, *Journal*

*Of Family Psychology*, 27 (2), pp. 242-251.

Rubin, H. and Rubin, I. (1995) *Qualitative interviewing: the art of hearing data*. London: SAGE Publications Ltd.

Rubin, Z. (1970) Measurement of romantic love, *Journal of Personality and Social Psychology*, 16 (2), pp. 265-273.

Rutter, M. (1981) *Maternal deprivation reassessed*. Harmondsworth: Penguin.

Rutter, M (1995) Clinical implications of attachment concepts: Retrospect and prospect, *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 36 (4), pp. 549–71.

Rutter, M., Quintin, D. and Hill, J. (1990) Adult outcomes of institution-reared children: males and females compared, in: Robins L. and Rutter, M. (eds.) *Straight and Devious Pathways from Childhood to Adulthood*. Cambridge: Cambridge University, pp. 135-57.

Ryan, J. and Thomas, F. (1987) *The politics of mental handicap*. London: Free Association Books.

Saguna, J. A. (2014) Disability: An embodied reality (or space) of *Dasein*, *Human Studies*, 37 (1), pp. 31-56.

Samuel, A. (2010) *The future of employment support for people with disabilities*. Available from: <http://www.communitycare.co.uk/articles/20/08/2010/115130/the-future-of-employment-support-for-people-with-disabilities.htm> [Accessed 9<sup>th</sup> February 2013].

Sandbrook, D. (2009) *White heat: A history of Britain in the swinging sixties 1964-1970*. London: Abacus.

Sandelowski, M. and Barroso, J. (1989) Writing the proposal for a qualitative research methodology project, *Qualitative Health Research*, 13 (6), pp. 781-820.

Schelly, D (2008) Problems associated with choice and quality of life for an individual with intellectual disability: a personal assistant's reflexive ethnography, *Disability and Society*, 23 (7), pp. 719-732.

Schofield, M. (1973) *Sexual behaviour of young adults*. London: Allen Lane.

Scruton, R. (1995) *A short history of modern philosophy: From Descartes to Wittgenstein*. New York: Routledge.

Sheeran, P. and McCarthy, E. (1990) The impact of unemployment upon self-conception: Evaluation, affection, consistency and involvement dimensions, *Social Behavior*, 5 (5), pp. 351-359.

Sears, R. R. (1957) *Patterns of child-rearing*. Evanston, IL: Stanford University Press.

Senn, T. E., Carey, M.P. and Venable, P. A. (2007) Childhood and adolescent sexual abuse and subsequent sexual risk behaviour: Evidence from controlled studies, methodological critique, and suggestions for research, *Clinical Psychology Review*, 28 (5), pp, 711-735.

Sex Education Forum (2003) *Sex and relationships education framework*. London: National Children's Bureau for the Sex Education Forum.

Sex Education Forum (2011) CURRENT status of sex and relationships education. Available from: [http://www.ncb.org.uk/media/385195/current\\_status\\_of\\_sre.pdf](http://www.ncb.org.uk/media/385195/current_status_of_sre.pdf) [Accessed 8th August 2014].

Shackelford, T. K., Schmitt, D. P. and Buss, D. M. (2005) Mate preferences of married persons in the newlywed year and three years later, *Cognition and Emotion*, 19 (8), pp. 1262-1270.

Shakespeare, T. (1993) Disabled peoples' self-organisation: A new social movement?, *Disability, Handicap and Society*, 8 (3), pp. 249-264.

Shaver, P. R., Hazan, C. and Bradshaw, E. (1988) Love as an attachment process, in: Sternberg, R. J. and Barnes, M. L. (eds.) *The psychology of love*. New Haven, CT: Yale University Press, pp. 68-99.

Shewan, L., McKenzie, K., Quayle, E. and Crawley, R. (2012) A qualitative exploration

of the identities of parents with a learning disability, *British Journal of Learning Disabilities*, 42 (1), pp. 17–24.

Simpson, G. and Price, V. (2010) From inclusion to exclusion: some unintended consequences of Valuing People, *British Journal of Learning Disabilities*, 38 (3), pp. 180–186.

Simpson, J. A. (1990) Influence of attachment styles on romantic relationships, *Journal of personality and social psychology*, 59 (5), pp. 971-980.

Simpson, J. A., Ickes, W., and Grich, J. (1999) When accuracy hurts: Reactions of anxious-ambivalent dating partners to a relationship threatening situation, *Journal of Personality and Social Psychology*, 76 (5), pp. 754–769.

Simpson, J. S. and Rholes, W. S. (1998) *Attachment theory and close relationships*. New York: Guilford Press.

Sinclair, I., Baker, C., Lee, J. and Gibbs, I. (2007) *The pursuit of permanence: A study of the English care system*. London: Jessica Kingsley Publishers.

Singh, D. and Young, R. K. (1995) Body weight, waist-to-hip ratio, breasts, and hips: Role in judgments of female attractiveness and desirability for relationships, *Ethology and Sociobiology*, 16 (6), pp. 483-507.

Smith, A., Flowers, P. and Larkin, M. (2009) *Interpretative phenomenological analysis: theory, method and research*. London: SAGE Publications Ltd.

Smith, H. and Brown, H. (1992) Defending community care: Can normalization do the job?, *British Journal of Social Work*, 22 (6), pp. 685–693.

Smith, J. A. and Eatough, V. (2007) Interpretive phenomenological analysis, in: Lyons, E. and Coyle, A. (eds.) *Analysing Qualitative Data in Psychology*. London: SAGE Publications Ltd, pp. 35-50.

Smith, J. E., Waldorf, A. V. and Trembath, D. L. (1990) "Single white male looking for thin, very attractive...", *Sex Roles*, 23 (11-12), pp. 675-685.

Smyth, C. M. and Bell, D. (2006) From biscuits to boyfriends: The ramifications of choice for people with learning disabilities, *British Journal of Learning Disabilities*, 34 (4), pp. 227–236.

Social Care Institute for Excellence (2005) *Helping parents with learning disabilities in their role as parents*. Available from:

<http://www.scie.org.uk/publications/briefings/briefing14/index.asp> [Accessed 8th August 2014].

Social Care Institute for Excellence (2012) *At a glance 60: Preventing loneliness and social isolation among older people*. Available from:

<http://www.scie.org.uk/publications/ata glance/ata glance60.asp> [Accessed June 2013].

Soper, B., Milford, G. E. and Rosenthal, G. T. (1995) Belief when evidence does not support theory, *Psychology and Marketing*, 12 (5), pp.415-422.

Sparrow, S., Balla, D. and Cicchetti, D. V. (1984) *The Vineland Adaptive Behaviour Scales*. Circle Pines: American Guidance Service.

Special Friends Online (2010) Available from:

<http://www.specialfriendsonline.com/public/> [Accessed 8<sup>th</sup> February 2013].

Spiller, S. (2014) *Europe's hidden shame*. Available from:

<http://www.aljazeera.com/programmes/peopleandpower/2014/04/europe-hidden-shame-2014414124139195247.html> [Accessed 26th September 2014].

Sprecher, S. and Regan, P. (2002) Liking some things (in some people) more than others: Partner preferences in romantic relationships and friendships, *Journal of Social and Personal Relationships*, 19 (4), pp. 463-481.

Stalker, K., Baron, S., Riddell, S. and Wilkinson, H. (1999) Models of disability: the relationship between theory and practice in non-statutory organizations, *Critical Social Policy*, 19 (1), pp. 15-29.

Stanley, N., Manthorpe, J. and Penhale, B. (1999) *Institutional abuse: perspectives across the life course*. London: Routledge.

Stenfert Kroese, B., Hussein, H., Clifford, C. and Ahmed, N. (2002) Social support networks and psychological well-being of mothers with intellectual disabilities, *Journal*

*of applied research in intellectual disabilities*, 15 (4), pp. 324-340.

Sternberg, R. L. (1996) Construct validation of a triangular love scale, *European Journal of Social Psychology*, 27 (3), pp. 313- 335.

Sternberg, R. J. (2000) *Handbook of intelligence*. Cambridge: Cambridge University Press.

Stonewall (no date) *History of lesbian, gay and bisexual equality*. Available from: [http://www.stonewall.org.uk/at\\_home/history\\_of\\_lesbian\\_gay\\_and\\_bisexual\\_equality/default.asp](http://www.stonewall.org.uk/at_home/history_of_lesbian_gay_and_bisexual_equality/default.asp) [Accessed 13th September 2014].

The Sunday Morning Herald (2010) *Sex out friendship in: Survey*, The Sunday Morning Herald. Available from: <http://www.smh.com.au/lifestyle/life/sex-out-friendship-in-survey-20100504-u4a1.html> [Accessed 8th March 2013].

Swango-Wilson, A. (2008) Caregiver perceptions and implications for sex education for individuals with intellectual and developmental disabilities, *Sex and Disability*, 26 (2), pp. 75–81.

Tarleton, B., Ward, L. and Howarth, J. (2006) *Finding the right support. A review of issues and positive practice in supporting parents with learning difficulties and their children*. London: Baring Foundation.

Tavistock and Portman NHS Trust (2011) *Men 'worried' about heavy internet porn use*. Available from: <http://www.bbc.co.uk/newsbeat/12918531> [Accessed 16th March 2013].

Teddlie, C. and Yu, F. (2007) Mixed methods sampling: A typology with examples, *Journal of Mixed Methods Research*, 1 (1), pp. 77- 100.

Terry, L. and Campbell, A. (2009) Family myths of a child's identity and the effect on service provision, *Learning Disability Practice*, 12 (8), pp. 24-29.

Thelen, M. H., Vander Wal, J. S., Muir Thomas, A. and Haron, R. (2000) Fear of intimacy among dating couples, *Behaviour Modification*, 24 (2), pp. 223-240.

Thome, B., Esbensen, B. A., Dykes, A.-K. and Hallberg, I.R. (2004) The meaning of cancer in old age, *European Journal of Cancer Care*, 13 (5), pp. 399–408.

Towell, D. (1980) *An ordinary life in practice: developing comprehensive community-based services for people with learning disabilities*. London: King Edward's Hospital Fund for London.

Tuckett, A. (2004) Qualitative research sampling the very real complexities, *Nurse Researcher*, 12 (1), pp. 47-61.

Underwood, L. G. (2008) Compassionate love: A framework for research, in: Fehr, B., Sprecher, S. and Underwood, L. G. (eds.) *The Science of Compassionate Love: Theory, Research, and Applications*. Malden, MA: Wiley-Blackwell, pp. 3-25.

Union of the Physically Impaired Against Segregation (1976) *Fundamental principles of disability*. London: UPIAS.

UK Youth Parliament (2007) *Sex and relationships education: Are you getting it?* Available from: [Sex and Relationships Education: Are You Getting It?](#) [Accessed 17<sup>th</sup> January 2013].

Van Ijzendoorn, M. H. and Kroonenberg, P.M. (1988) Cross-cultural patterns of attachment: A meta-analysis of the strange situation, *Child Development*, 59 (1), pp. 147-156.

Van Manen, M. (1990) *Researching lived experience. Human science for an action sensitive pedagogy*. New York: The State University of New York Press.

Vargas-Silva, C. (2014) *Migration flow of A8 and other EU migrants to and from the UK*. Available from: <http://www.migrationobservatory.ox.ac.uk/briefings/migration-flows-a8-and-other-eu-migrants-and-uk> [Accessed 23rd September 2014].

Waite, L.J. (1995) "Does marriage matter?", *Demography*, 32 (4), pp. 485-507.

Walker, E. C., Holman, T. B. and Busby, D. M. (2009) Childhood sexual abuse, other childhood factors, and pathways to survivors' adult relationship quality, *Journal of*



*Family Violence*, 24 (6), pp. 397–406.

Walmsley, J. (2004). Inclusive learning disability research: the (nondisabled) researcher's role, *British Journal of Learning Disabilities*, 32 (2), pp. 65-71.

Walmsley, J. and Johnson, K. (2004) *Inclusive research with people with learning disabilities: Past, present and future*. London: Jessica Kingsley Publishers.

Webb, C. (1992) The use of the first person in academic writing: objectivity, language and gatekeeping, *Journal of Advanced Nursing*, 17 (6), pp. 747–752.

Weeden, J., and Sabini, J. (2005) Physical attractiveness and health in Western societies: a review, *Psychological Bulletin*, 131 (5), pp. 635- 653.

Wells, B. E. and Twenge, J. M. (2005) Changes in Young People's Sexual Behavior and Attitudes, 1943–1999: A Cross-Temporal Meta-Analysis, *Review of General Psychology*, 9 (3), pp. 249–261.

Wechsler, D. (1944) *The measurement of adult intelligence*. Baltimore: Williams and Wilkins.

Weisner, T. S. and Gallimore, R. (1977) My brother's keeper: Child and sibling caretaking, *Current Anthropology*, 18 (2), pp. 169-190.

White, E. and Barnitt, R. (2000). Empowered or discouraged? A study of people with learning disabilities and their experience of engaging in intimate relationships, *The British Journal of Occupational Therapy*, 63 (6), pp. 270-276.

Williams, S. J. (1999) Is anybody there? Critical realism, chronic illness and the disability debate, *Sociology of Health and Illness*, 21 (6), pp. 797–819.

Wind, T. W. and Silvern, L. (1992) Type and extent of child abuse as predictors of adult functioning, *Journal of Family Violence*, 7 (4), pp. 261-281.

Wolfe, P. (1997) The influence of personal values on issues of sexuality and disability, *Sexuality and Disability*, 15 (2), pp. 69-90.

Wolfensberger, W. (1972) *The principle of normalisation*. Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1983) Social role valorization: a proposed new term for the principle of normalization, *Mental Retardation*, 21 (6), pp. 234–239.

Wood, A. and Grieg, R. (2010) *Supported Living – Making the move. Developing supported living options for people with learning disabilities*. Bath: National Development Team for Inclusion

Working Together with Parent Network (2009) *Supporting parents with learning disabilities and difficulties – Stories of positive practice*. Bristol: Norah Fry Research Centre

World Health Organisation (1980) *International classification of impairments, disabilities and handicaps*. Geneva Switzerland: World Health Organisation.

Wright, D. and Digby, A. (1996) *From idiocy to mental deficiency: Historical perspectives on people with learning disabilities*. New York and London: Routledge

Zentner, M. and Mitura, K. (2012) Stepping out of the caveman's shadow: Nations' Gender Gap predicts degree of sex differentiation in mate preferences, *Psychological Science*, 23 (10), pp. 1176-1185.

### **UK- Acts/ Laws**

Abortion Act 1967

Asylum and Immigration Appeals Act 1993

British Nationality Act 1948

Care Standards Act 2000

The Chronically Sick and Disabled Persons Act 1970

Commonwealth Immigrants Act 1962

Civil Partnership Act 2004

Disability Discrimination Act 1995

Education Act 1996

Equality Act 2010  
European Convention for Human Rights Act 1998  
Human Fertilisation and Embryology Act 2008  
Idiots Act 1886  
Local Government Act 1988  
Lunacy Act 1845  
Lunacy Act (Ireland) 1871  
Mental Health Act 1959  
Mental Deficiency Act 1913  
Mental Deficiency Amendment Act 1927  
Mental Capacity Act 2005  
National Health Service (Family Planning) Act 1967  
NHS and Community Care Act 1990  
Poor Law Amendment Act 1834  
Public Interest Disclosure Act 1998  
Registered Homes Act 1984  
Royal Commission on the Care and Control of the Feeble-minded - Radnor Report 1908  
Sexual Offences Act 1956  
Sexual Offences Act 2003  
Sexual Offences Act (Ireland) 1993  
Welfare State and National Assistance Act 1948  
Youth Justice and Criminal Justice Act 1999

## Appendices

## **Appendix 1 - What do people look for in a partner? Typology of Western Research**

No research specifically identified the traits valued in a partner by people with learning disabilities. Therefore, this Section draws solely on research with people without a learning disability. A typology was undertaken to establish what people without a learning disability desired in a potential partner, to provide later a comparison between people with and without learning disabilities. The typology included:

- 20 research studies;
- 15 from academic research
- 5 from large-scale research studies compiled by dating websites or national press

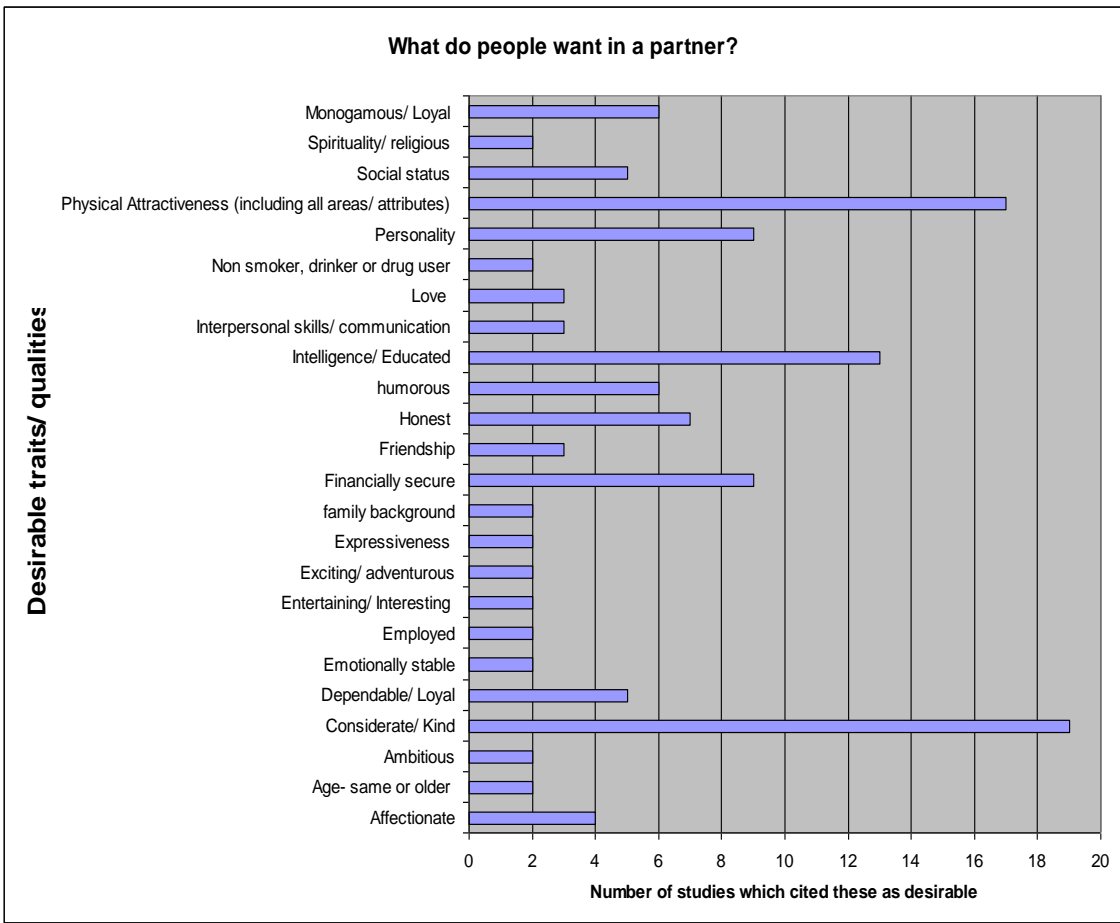
See Appendix 1 for Tables outlining the research included in the typology including year, county, sample age, sex, ethnicity and geographical location.

### **Most desired traits / attributes in a relationship**

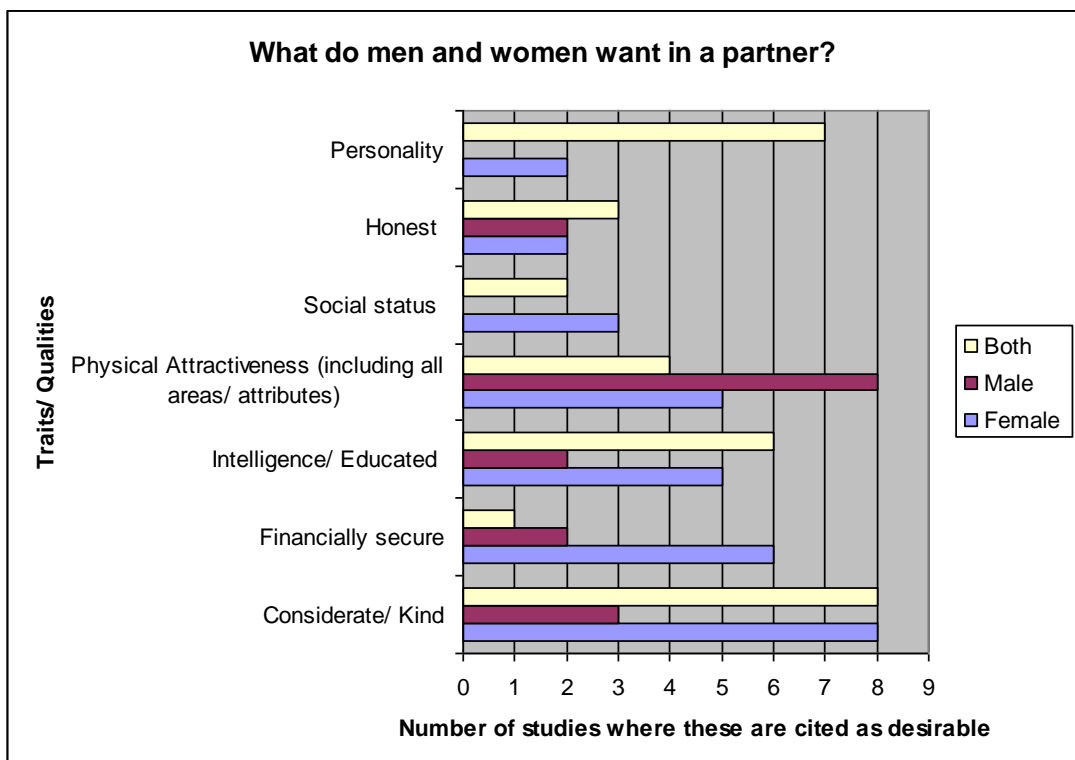
Graph 1 depicts the traits/qualities which were most desired as highlighted in the data by both sexes. Considerate/kind partners were valued the highest, followed by physically attractiveness (all references to physical beauty were included here) and thirdly, individuals valued partners who were intelligent/well educated. Partners who had a good personality and who were financially secure were also seen as appealing, as were those who were honest and loyal/monogamous.

Graph 1 demonstrates that kindness and consideration was valued as important by both sexes. Both sexes valued a partner who displayed traits similar to the attachment figure in childhood. Shackelford *et al.*, (2005) stated that both sexes sought partners 'high in agreeableness, conscientiousness, and emotional stability' (p.1269). As discussed in Sections 2.2.1 and 2.2.2, it is the ability to be kind and considerate which enabled intimacy and love to develop between couples. There was no literature available which explored whether people with learning disabilities valued kindness and consideration in a partner, however considering the high levels of abuse experienced by people with learning disabilities in relationships (McCarthy, 1999), it would be correct to assume that this was something they would have valued highly.

**Graph 1- What do people want in a partner**



**Graph 2- Difference between Sexes**



Graph 2 presents the traits rated as desirable by male and female participants. Male participants were more likely to value physical attractiveness however this was also important to women. Women valued financial security, social status and intelligence/education higher than their male counterparts did. This reflected a more traditional view of the man providing for women despite many women achieving financial independence.

As depicted in graph 2 there was evidence to suggest that both male and female participants reflected some stereotypical selections when stating what traits they valued in a partner. Despite the advances of feminism, the women's liberation movement and the societal changes towards the 'objectification' of women, men continued to value the physical appearance of a partner highly. This was identified in numerous pieces of research such as Buss and Barnes (1986) and almost twenty years later in Shackelford *et al.* (2005). Shackelford *et al.*'s research focused on young newlyweds (in their first marriage) and, when re-interviewed after three years, aesthetics appeared less important as a 'pleasing disposition' was rated much higher than when newly married. This suggested couples come to appreciate how important it was to have a spouse 'who is high in agreeableness, conscientiousness, and emotional stability' (p.1269). Young adults (18-24 years old) made up half of the participants in research for this typology, which suggested that although young males (and possibly females to some extent) may value attraction initially there was evidence to suggest this became less important over time in a relationship. This supports Berscheid and Walster's (1978) concept of companionate love, that over time it is more important to have a partner with whom you could develop an emotional bond and be intimate with rather than an intense passion.

Like men women also displayed some gender stereotypical responses. Women cited 'dependability and financial security' as a desirable trait, which suggested that despite advances in society with many women in high earning job roles, the Equal Pay Act (1970) and the Equality Act (2010), there was still a desire for a man to fulfil the role of providing for the female economically. Despite this, O'Reilly *et al.* (2009) argued that society was moving away from this traditional ideal and women were selecting men with more 'expressive' qualities which they defined as 'consideration, dependability, and intelligence' (p.503). O'Reilly *et al.*'s findings suggested women were searching for men with whom they could build a strong emotional and intimate bond. However

O'Reilly et al.'s (2009) sample consisted of mainly white college students in the USA and, due to the cost of a college education, it was most likely that participants were not poor. It was possible that due to their educated status they preferred men who were more sensitive and intelligent as this was what was valued in their Section of society and being college students it was likely they could sustain themselves making redundant the need for a man to provide financially. Had the research been conducted with a more varied sample, such as older, non-white or lower economic status Americans, other traits may have been valued higher.

No research was located which identified whether financial security was valued by women with a learning disability in male partners. However considering that only 7.1% of adults with a learning disability are in paid employment, compared to the general population 67% (males) and 57% (females) (Emerson *et al*, 2012), it may not have been as important for men to be financially sufficient as it was for women without a learning disability, possibly as it was not expected or 'the norm'. Also fewer women with learning disabilities have children to provide for: there were no exact figures, however, it was estimated that there were approximately 53,000 families in England where at least one parent had a learning disability (Bristol University, 2008).

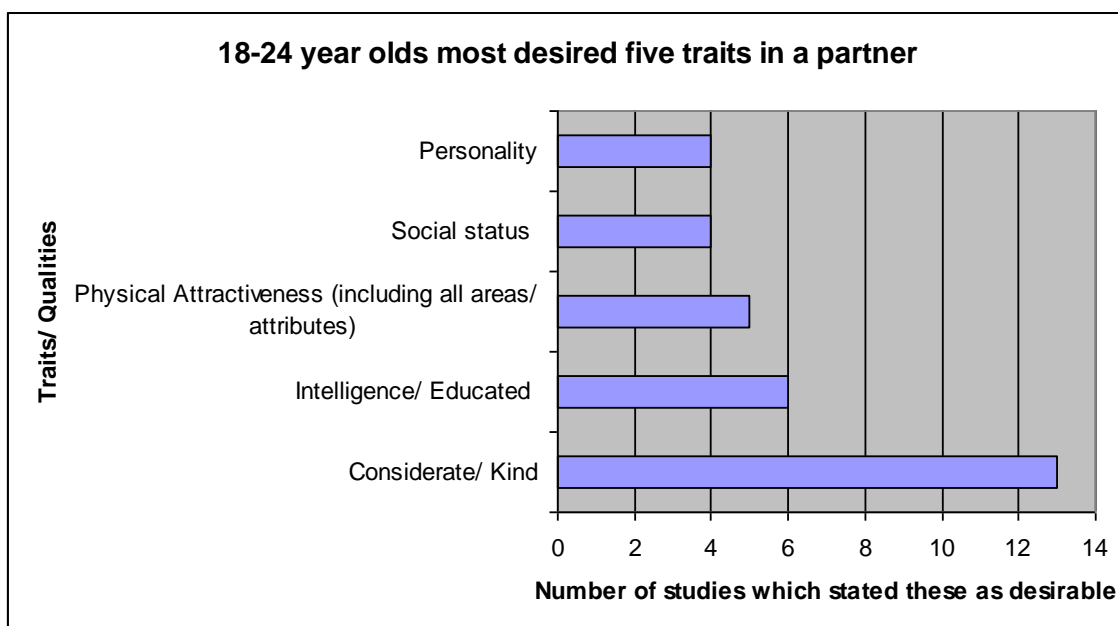
Research by Zentner and Mitura (2012) argued that culture rather than gender was most significant in partner selection. This research was not included in the typology as it included countries outside of those highlighted in Section 2.1. This could have been problematic in terms of comparisons between cultures of developing and developed nations, however their results regarding the impact of gender and equality on partner selection were considered relevant for discussion. The research included 3,177 respondents from 10 countries and it established that in countries where there were higher levels of gender equality there were fewer differences in partner selection between genders. In high gender-equal societies, participants were less likely to value the traditional traits associated with their gender. It was not stated whether Zentner and Mitura (2012) research included homosexual people, making it unclear how their theory could be applied to this group of individuals. Zentner and Mitura (2012) acknowledged that other factors including religion, economics, geography and demographics could have provided an alternative explanation for their findings. They argued these factors 'work through an association with gender equality' (p.8) but this association was not sufficiently explained to allow an understanding of how this worked. Their significance was also not truly acknowledged, especially for factors such as religion and economics



in countries such as Nigeria compared to countries such as Sweden. However, their results were replicated in a second study with 8,953 respondents from 31 nations. Such a large-scale study suggested a high level of reliability and trustworthiness.

The importance of culture in partner selection was also referenced by Levitt (2006) who demonstrated that women valued partners similar to themselves in terms of cultural, religious, and social beliefs and who shared their world view. Levitt (2006) argued that a similarity in culture and beliefs increased trust in relationships. It could be argued that people with learning disabilities have their own culture based on shared experiences and a shared history which excludes adults without a learning disability to some extent. This shared culture could be influential for people with learning disabilities when selecting a potential partner and according to Levitt (2006) this would possibly increase trust in their relationship. However, Levitt's (2006) research also explored the characteristics of those from a Caucasian Christian background and it was possible that those who defined themselves as religious may place more significance on a shared culture than those who did not. The exploration of the views of people who were not Caucasian could have demonstrated some variation in what was valued in a partner. Two thirds of the sample were friends or colleagues of the researcher and they felt 'increased comfort' (Levitt, 2006, p.454) in sharing intimate details but the possible negative affect was not discussed. For example it may have affected how willing they were to be honest by exposing any negativity or tension within their relationship to someone they saw informally.

**Graph 3- Differences in Age Range**



Young adults (18-24 years old) were the largest age range: half of the research studies recruited participants in this group and their results are displayed in Graph 3. The use of students (aged approximately between 18-22 years) as a sample was more typical in older research (1980s-pre 2000): six of the eight studies samples conducted in this period consisted of students compared to four out of thirteen in newer research (post-2000). This use of students as a sample could have been criticised for being used for the researchers' ease, using a ready-made sample and lacking diversity. When the older research was conducted students could have been considered the most appropriate age range to sample as the average age for marriage has been increasing with time. 'For grooms, the mean age at marriage in 1970 was 27.2 years, compared with 36.2 years in 2010. Women have seen a similar general increase, from 24.7 years in 1970 to 33.6 years in 2010' (Office for National Statistics, 2012).

King and Allen (2009) was the only research that focused on black men and women in their early thirties. The research was self-selecting and women were significantly over-represented in the sample. The research produced comparable findings to the younger groups but they rated loyalty/monogamy as highly desirable. This difference may be due to a change in culture or in focus within a relationship, possibly the starting of a family or having experienced some form of relationship breakdown or betrayal. According to the Office for National Statistics (2010) 'Babies born in England and Wales in 2010 were most likely to have a mother aged 25–34, with over a half (56 per cent) of mothers being in this age group' (p1). This could influence the significance of loyalty/monogamy to women as this would be important to those considering a starting a family which was most common within their age group. However this could also be seen as a factor in older age ranges as the trend for motherhood in later life increases: in 2010 20% of babies born in the UK were to women over 35 years old (Office for National Statistics, 2010).

Both male and females in King and Allen's (2009) sample placed significant focus on wealth, which was not rated as important by younger participants. Both males and females wanted their ideal partner to earn more than them thus enhancing their economic status, which was not a typical desire for males. Participants in this research were wealthier than the average African American. King and Allen (2009) therefore claimed the sample was not representative and the findings should be applied cautiously to the wider population. King and Allen's (2009) research highlighted the

specific issues faced by African Americans, such as over-representation in the criminal justice system and typically lower economic status. Caucasians were over-represented in partner selection research: the literature review did not identify any UK research which examined black British men or women. This made the application of King and Allen's (2009) findings to the UK population questionable as the situation for black British people may be different to the USA.

Two studies included 35-50 year olds', Levesque and Caron (2004) as a second sample group and an eHarmony survey (2009). Levesque and Caron (2004) identified that women in this age group were more flexible regarding age, marital status and education than were younger participants. Levesque and Caron (2004) concluded that this group was less focused on education or wealth as they did not require a man to attain this and were confident in their own status. Despite this flexibility, they were not 'desperate' for marriage but had not married either because they had not met the correct person or did not desire this. The biological aspects of finding a mate to procreate with did not appear to be a factor. The women did not desire to marry before it was too late to conceive. 'These women were comfortable with their own ability to take care of themselves, and they were looking for qualities in a partner that would accommodate or enhance their lives' (Levesque and Caron, 2004, p.844). The research only included females so it was unclear if the same findings would be found among men or in ethnic minorities as almost all women in the sample were white educated women. It was possible there would be more pressure to marry within ethnic minorities to marry, for example in South Asia and China marriage 98% of men and women marry (*The Economist*, 2011).

The eHarmony survey (2009) for a dating site also examined the preference of women over 35 years old. The survey referenced different qualities to other research such as spirituality/religion, non-smoker/drug user and similar/older age, which were inconsistent with the other age ranges. This suggested women over 35 years old valued different characteristics (*The Sunday Morning Herald*, 2010). This was a large-scale questionnaire survey conducted by a dating website, eHarmony, which prides itself on 'individuality'. It was possible that the traits within the questionnaire were pre-selected to be more 'unique' in nature thereby introducing bias. The majority of the academic research into partner selection was conducted in late 1980s to early 2000s (5-1980s, 3-1990s, 6-pre 2005 and 7-post 2005). Half of those conducted post 2005 were conducted via non-academic mediums such as surveys in magazines and via

dating websites. This was unsurprising given that in 2011 two thirds of UK singles have tried on-line dating (John, 2011). Non-academic research could be criticised as it lacked the rigor of academic research, however the five non-academic surveys reached high numbers and, given that most were for dating websites, it is highly possible that people would be more honest here as their selected preferences would have an impact on their actual 'partner selection'.

In summary, the most valued traits in a partner across sexes and ages were kindness and consideration. All participants wanted someone who was kind to them, considered their feelings and had the ability to form a close emotional bond. This resonated with Lee's (1973) love style 'Storge' that was focused on a friendship-based love as well as Berscheid and Walster's (1978) companionate love that was associated with positive emotions such as tenderness and affection (Section 2.2.1). The desire for a close emotional bond demonstrates the importance of intimacy (Rubin, 1970, Sternberg, 1996). Attractiveness was important, especially to men, in partner selection but this reduced as the relationship progressed or people aged. Reflecting on the findings suggested that 'stage of life' was more influential than age in determining what a person desired in a potential partner. Individuals' age, history and experiences could determine when they felt ready to commit to a relationship, resulting in a shift in their head/heart due to a change in circumstances. Social history could influence when this 'change' occurred, as is evident in the trend for increasing age for marriage and childbearing.

## Typology Data

No.	Name	Year	Country	Title	Sample Age	Sample size/ sex	Location	Ethnicity
1a	Buss, D. M. and Barnes, M.	1986	USA	Preferences in Human Mate Selection	18 and 40 years old-	92 Married couples	USA - large metropolitan area	Unknown
1b	Buss, D. M. and Barnes, M.	1986	USA	Preferences in Human Mate Selection	18-23 years old	Students- 50 male 50 female	USA - University	Unknown
2.	Shackleford, T., Schmitt, D., and D. M., Buss.	2005	USA	Mate preferences of married persons in the newlywed year and three years later	The mean age of wives was 25.5 years, husbands was 26.8 years. Just married and 96% 1 <sup>st</sup> marriage	27 married couples	USA - in mid-western town	'Mainly Caucasian'
3.	Lacey; Reifman Pearson Scott, Harris and Fitzpatrick	2004	USA	Sexual-Moral Attitudes, Love Styles, and Mate Selection	87% 18-23 years old- 12% 24-59 years old	330 students (77% females, 23% males)	USA - South western University	85%- White, Hispanic (8%) and Black (4%).
4.	O'Reilly, Sarah, Knox,	2009	USA	What college women want in a marriage partner	The median age of the respondents	197 students - 71% female and 29% male	USA -	80% white and 20% non white

	David, Zusman, Marty				was 19 (age range 17 to 48)			
5.	Katherine Andrinopoulos, Deanna Kerrigan and Jonathan M. Ellen	2006	USA	Understanding Sex Partner Selection From the Perspective of Inner-City Black Adolescents	Young Adults 16-21 years old (Average age 18)	4 male and 4 female	USA - Inner City Location Baltimore	All Black Americans
6.	Hoyt, L. L. and Hudson, J.	1981	USA	Personal characteristics important in mate preferences among college students	Mean age female 20 mean age male 21	132 males 184 females	USA - university	Doesn't say – assume in 1981 majority of students were white
7,	Regan, P.	1998	USA	What if you can't get what you want? Willingness to compromise ideal mate selection standards as a function of sex mate value and relationship context.	Doesn't say but undergraduate students	72 (32 Males and 40 females)	USA - university	56% Caucasian 15.3% Latino 13.9% Asian 13.9% African American

8.	Stimpson, J and Gangstade, S.	1992	USA	Socio-sexuality and romantic partner choice	Students	221 male students and 252 Female students	Texas University	Unknown
9.	EHarmony dating Website	2009 ?	Australia	What singles want in a partner (possibly unable to find actual report)	Australian eHarmony users over 35 years old	150, 000 users	Nationwide in Australia	Unknown
10.	PARNSHIP	2009	UK	Unknown	Unknown	13,000 men and women	Europe	Unknown
11.	Ebony Magazine Survey  <a href="http://findarticles.com/p/articles/mi_m1077/is_2_56/ai_67531410/">http://findarticles.com/p/articles/mi_m1077/is_2_56/ai_67531410/</a>	2000	USA	What Black Men Really Want	Unknown	1,000 men	USA	Black American Men
12.	www.ukdating.com  <a href="http://www.dailymail.co.uk/news/article-530361/Blu">http://www.dailymail.co.uk/news/article-530361/Blu</a>	Unknown but between 2006-2008	UK	Unknown but around what men want in a partner	Unknown	66,000 men	UK	Unknown

	<a href="#">e-eyes-blonde--good-bed-What-men-REALLY-look-ideal-woman.htm!</a>							
13.	LEVESQUE and Caron	2004	USA	Dating Preferences of Women Born Between 1945 and 1960	2 groups -20-25 years - 35-50 years	81 Women	Eastern and central Maine USA	All but 3 of the 81 women were white (the other 3 were native American)
14.	MORE Magazine	2008	UK	The Young Women's Relationship Survey	Young Women (under 30 years old)	2,400	UK	Doesn't say
15.	Smith, Waldorf and Trembath	1990	USA	Single white male looking for thin very attractive...	Doesn't say	283 male and 231 female from personal ads in mag- 'The Scene'	USA	Doesn't say
16.	Goodwin, R.	1990	UK	Sex Differences Among Partner Preferences: Are the Sexes Really	Study 1- 1 <sup>st</sup> year students (approx 18-19 years)	Study 1 216 single students, (129 female/ 87 male)	Study 1- Uni of Kent	Doesn't say



				Very Similar	Study 2- 18-27 years old	Study 2- 76 dating agency members (38 m/f)		
17.	Sprecher and Regan	2002	USA	Liking some things (in some people) more than in others. Partner preferences in romantic relationships and friendships	Students Mean age 20.1 years	700 Students 59% women 41% men 98% Heterosexual	Mid-western university	Doesn't say
18.	King and Allen	2007	USA	Personal Characteristics of the Ideal African American Marriage Partner A Survey of Adult Black Men and Women	Primarily women in early 30's and well educated  61% women 39% men	334 American adults	North-eastern Ohio and western Pennsylvania-questionnaires distributed all over local community	All African American
19.	Nevid, J.	1984	USA	Sex Differences in Factors of Romantic Attraction	Students Mean age 21.5 years	328 males 307 females  Heterosexual	University students private university in New York suburbs psychology course	Doesn't say

20	Regan, P and Anupama	2003	USA	Ideal Partner preferences among adolescents	mean age-15.9 years (aged 14-16 years)	20 teenage girls and 26 boys	From public high school in LA	Mixed (43.5% white and 57% ethnic minorities)
----	----------------------	------	-----	---	--	------------------------------	-------------------------------	---

## **Appendix 2 - Information sent to Gatekeepers**

### **Learning Disabled Individuals Experience of Partner Selection and Relationships**

#### **Aims of the Research**

The research will focus on the intimate heterosexual relationships of adults with learning disabilities. Its three main aims are:

- To ask people with learning disabilities about what they look for in a potential partner
- To explore what makes some relationships more positive than others
- To gain a better understanding of what are the experiences of people with learning disabilities within relationships

#### **Research Method and Methodology**

The research methodology that will be used is Interpretive Phenomenological Analysis (IPA). The method will be individual in-depth interviews where people with learning disabilities will share their experiences of intimate relationships. Approximately 8-10 people will be interviewed, each interview lasting up to an hour each time and each person will be interviewed more than once and up to a maximum of 4 interviews. The participants will all be adults with a learning disability. To be included in the proposed study participants must meet a set number of criteria:

**They must have been in receipt of a specialist service for people with learning disabilities at some point in their life.**

**They must be able to communicate verbally to a high level.** Participants who will be included in the research will be adults with mild/moderate learning disabilities. The World Health Organisation defines an adult with a mild learning disability as having an IQ of between 50-70 and a person defined as having a moderate learning disability with an IQ between 35-50.

**They must have had at least one 'long-term' relationship (3 months +)** This does

not have to be sexual but must be a long standing heterosexual romantic/intimate commitment.

A gatekeeper will be used in the recruitment of participants. These will be people who have regular and direct contact with the potential participants. There are two locations for participant selection and these include:

**Provider 1** – This group contains potential participants from a ‘parenting group’ run by a facilitator for parents with a learning disability **(run by a charity organisation in Nottingham)**.

**Provider 2-** This group contains potential participants who receive support from staff in a residential setting **(run by a charity organisation in London)**.

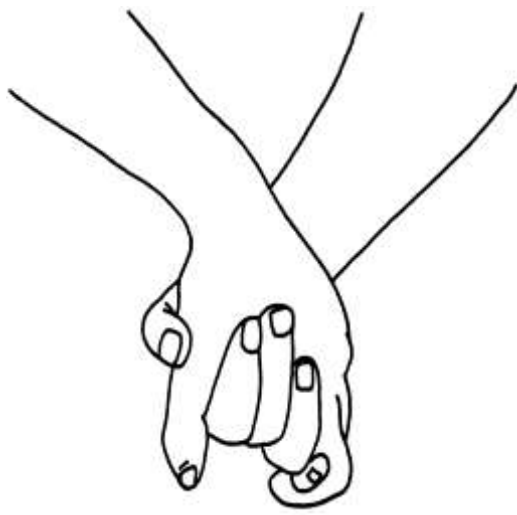
**In Provider 1-** The gatekeeper will be the parent group facilitator, (an employee of the organisation which runs the group) with experience of leading support groups for people with learning disability. I will contact the gatekeeper directly through their Director and discuss the research with them and how people are to contact me to become involved. I have created accessible information/easy read leaflets for both the potential participants and other people who are supporting them. It will be the role of the gatekeeper to use their knowledge of the group members to recommend this research to the appropriate people individually and not to include people who they know have been traumatised from a previous relationship. Due to the nature of the group they will have some knowledge of the potential participants’ background, their ability to share their thoughts and feelings as part of a group and also their level of ability in regards to communication skills.

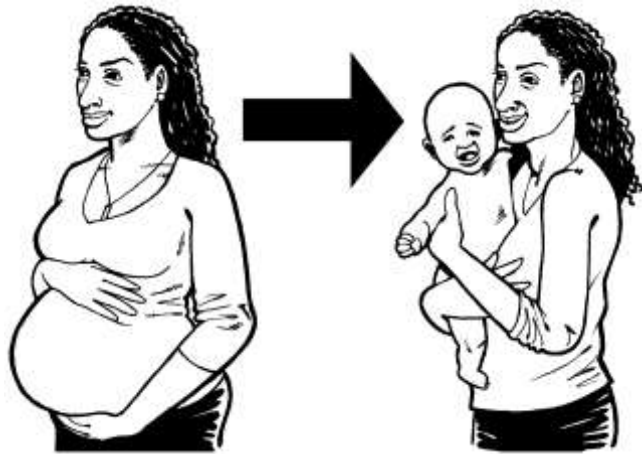
**In Provider 2 -** The gatekeeper will be a senior manager with direct knowledge and contact with participants. I will contact the senior managers directly via the company’s Chief Executive. I will speak to them directly about the research. Gatekeepers in this group have more knowledge of potential participants due to the level of contact and involvement they have within these individuals’ lives and should, therefore, be able to recommend appropriate people to be involved.

### **Informed Consent**

**Gatekeepers will not be giving consent for participants; people will be doing this for themselves.** All participants will be introduced to me via the gatekeepers. We will meet to discuss the research and they will be briefed about how the research may, potentially, make them feel and have the space to discuss any concerns they may have. People will be asked 'why shouldn't they take part?', to help the researcher to judge how much participants understand about the potential risk to them. Participants will also be asked 'why do you want to take part in the research'? They must provide an answer which reflects their own wishes rather than that of someone else such as a staff member or parent to be included in the research.

Appendix 3 - Change Picture Bank Cards – Shrunk Down- Actual Size A4





## **Appendix 4 - Interview Prompts**

These are general areas of interest and prompts rather than actual questions.

### **General relationship questions to gauge a person's understanding of the concept**

- What does relationship (boyfriend/girlfriend) mean to you?
- How would you describe a 'good relationship'?
- What would it look like/feel like?
- Have many of your friends with learning disabilities had relationships?
- Do you think people with a learning difficulty should get married/have children? Would you like this?
- Did you get any help/advice from support staff around being in relationship? If so, what type of support?
- How did it help/not help?
- Have you ever been stopped from having a partner/boyfriend/girlfriend?
- If so, how was that experience and what did it feel like?
- Why did they stop you: are they good friends/relatives etc'?
- If single/not living with someone- can they come and stay overnight and sleep in your room?
- If not, how does that make you feel?
- What do you think that means?
- Does where you live make it easy or hard to have a relationship?
- What do you think other people (general public) think about people with learning disabilities having relationships?
- What has been your experience (question above)?

### **Partner Choice**

- What would your ideal partner be like?
- Do you have a 'type' of person you date? If so, can you describe this type?
- Who would they treat you?
- What would they do (job)?
- What would they look like?
- What do you look for in a partner?



- Have you had a relationship with someone like who is like this? (the person you described above)

### **Current relationship**

- Are you in a relationship now?
- Where/how did you meet?
- How long have you been together?
- What is it like to be in a relationship? (your experience)
- Describe your partner – physical attributes/characteristics/lifestyle?
- What is it like to be with him/her?
- How does being with him/her make you feel?
- What types of activities do you do together/ Current living situation?
- What degree of physical contact (sexual relationship or not) do you have with your current/previous partner/s?
- Does this feel right for you?
- What are your plans for the future in regards to your relationship?(marriage, children, live together etc)
- What would you like things to be like for you and your partner in the future?
- What was your family/friends/staff reaction to your current/previous relationship/s?
- How did that make you feel?
- Does that affect you and your partner's relationship? How?
- What is the best thing your partner/ previous partner?
- Is there anything that you do not like about your partner/ relationship?
- What might you change to make your relationship (your experience of being in a relationship) better?

### **Previous relationships**

- Have you had any other relationships?
- What were they like?

Similar question as above but also

- Why did the relationship end?

- What did that feel like?
- Do you think you learnt anything from that (the experience of a relationship ending)?
- Who decided to end the relationship and why?
- Did you get any support/help after the end of the relationship? If so, what type of support?
- How did that support help you (or not help) in your experience of a 'break-up'?
- Did you talk about the break up with anyone? If so, who?
- Have you seen the person since? If so, what was that like?

## **Appendix 5 - First Interview**

### **First Interview**

The original research proposal indicated the use of a pilot study prior to the commencement of the interviews. Following the decision to change methodologies from Interpretive Phenomenological Analysis (IPA) to Hermeneutic Phenomenology, which was more suitable with the nature of the research, the use of a pilot no longer appeared congruent with the design of the research. Max Van Manen (1997) made no reference to the use of a pilot in his writings. The use of a pilot is more common in IPA research as it is a methodology with very close links to psychology, where the pilot is used extensively. In psychology pilots are used to test research instruments such as questionnaires or interview schedules (Breakwell, 2006). Smith et al (2009) discuss the use of a pilot in their book 'Interpretative Phenomenological Analysis: Theory, Method and Research', claiming the pilot interviews should be used to learn the interview schedule. However in this research there is no interview schedule as it is exploratory in nature.

It was felt that a pilot study was not congruent with the research design and interviews were due to commence once ethical approval was gained. The first interview took place and a number of problems were encountered. It was decided that this interview would be used as a form of pilot where a period of reflection and evaluation could take place prior to any subsequent interviews. This process was intended to address the concerns raised in the first interview and assist in the preparation for the next interviews.

### **Participant**

He was a male in his late 30s/early 40s. He met the pre-defined inclusion criteria of being in receipt of a specialist service for people with learning difficulties (he lived a supported living house), he was able to communicate verbally and he had had at least one romantic relationship with a woman. He appeared to have a good understanding and use of language but this was hampered by a speech impediment. This initially raised concerns regarding his audibility in terms of recording and transcription.

## **Recruitment and Initial Meeting**

The participant was recruited via a gatekeeper in a provider organisation. It was a senior manager who recommended the participant and initial contact was made via the house manager. The initial meeting took place with the participant's girlfriend, who was also considering taking part at their home. Staff had spoken to both people prior to my approval and they were expecting me when I arrived.

The accessible research information sheet for participants was discussed. These had been sent to the property prior to the visit for staff to discuss with people to determine if people were interested in taking part. Both people I spoke to said they had not seen this and were not informed about what the research would involve. During this meeting the participant's current partner appeared disinterested and was not overtly engaging in the conversation despite attempts to include her. She said she would think about whether she wanted to take part and let the staff know. She decided not to take part as she felt it would be too personal. Staff informed me of this and explained she was a very private person. However, her partner confirmed he wanted to be involved in the research.

After reading the accessible information the participant was asked if he thought that he might get upset talking about quite personal things if he took part. He said he might get upset speaking about old girlfriends. He was asked to think about what he might do if that happened and if he thought he may get too upset to take part. He said he didn't think so but he would speak to the staff or his current girlfriend if he did. He appeared to have a good understanding of what the research would entail and was able to tell me about the kinds of activities he does with his current partner (where they go for dinner, etc). I said this would be good and I would come back with a recorder and we could talk about it more. From this meeting it was felt that the participant was able to make an informed decision about consenting to take part in the research. He was able to identify some of the negative aspects which could occur if he chose to take part but was still keen to be involved.

Following the initial meeting staff were contacted to arrange the interview they confirmed the participant was still keen to be part. When asked how he was likely to respond if he did not want to answer a question staff explained that he would most likely remain silent. Staff explained that he can get anxious speaking about ex-girl friends and it was explained that we had covered this in our initial meeting. Staff said it

would be possible to assess if the participant was becoming anxious as he shows clear physical signs and she said if this occurred the subject should be changed or a break taken.

## **Research Interview – Issues encountered**

### **Restricted content**

Upon arrival to conduct the first research interview the staff member who had been asked to discuss the interview content suggested that the interview should not include questions relating to past relationships. She felt the participant could get too distressed due to circumstances regarding his past relationships. Although this had been discussed prior to the research it had not been stated that this was an area which could not be discussed but should be approached with caution. She stated that the subject could be pursued if he brought it up himself. The staff member did not disclose what had made the past relationships so traumatic for this individual and it was not appropriate to ask. The interview began with the participant discussing having being 'accused of rape' (I think that was what he said). This was not pursued as what he said was quite unclear and I was concerned about responding as it felt ethically wrong (after what the staff had said). If the staff were aware of this then he should not have been approached to take part.

Being asked to restrict such a large Section of the intended interview material had a significant impact on the interview creating a feeling of restriction and inhibition. This experience was unsettling to a novice researcher about to conduct her first interview as part of a PhD thesis. It had a significant effect on the flow of the interview and increased levels of caution and trepidation to an unproductive level. The effect this had on the quality of the data produced will be discussed in more detail in another Section.

In hindsight, there were serious concerns about whether the interview should have gone ahead as the criterion was not to include participants who were traumatised by previous relationships. It was felt that the manager (acting as a gatekeeper) should have made a better assessment of the participant's suitability for the research: in their position they should have been able to use their knowledge of the person and his history to make a judgement. If the person was known to get very distressed he should not have been included.

As a researcher I also take some responsibility for his inclusion as I was aware of the issues prior to this but I thought that it was a manageable risk if I was observant for signs of anxiety and that the instructions from support staff were followed. The interview did proceed, excluding conversation of past partners, and the person was not distressed at any point (from my observations). This exclusion did have an impact on the data produced.

### **Interview Process**

The interview lasted 30 minutes, beginning with a small amount of 'chatting' about general things, such as the weather, journey to work, etc., to allow both the participant and myself time to warm up. A sound test was done using the microphone and laptop. The interview took place in the living room. No other persons, including staff, were present in the interview and this was at his request. The participant was asked again if he wanted to take part and he agreed, the confidentiality leaflet was explained again and he was informed that after the interview he could still be asked to be removed at any point and his data would be destroyed. The consent form was signed and is now locked in a secure cabinet.

The interview quickly established a familiar pattern of asking questions and the participant giving very short answers with some repetition. It felt too interrogatory, pursuing a number of different topics from the interview guide with limited success. This made the interview feel very disjointed and unfocused. Attempts were made to ask the same question in different ways for some questions but eventually the topic was discarded and another attempted, but the same pattern ensued.

Upon reflection, it was felt that the questions may have been too abstract: for example, when trying to find out what he found most attractive in a woman a range of questions were posed such as 'what would she look like?' 'what about her personality?' but the person had difficulty with this and found it easier when specific questions were asked 'what colour hair/ eyes?' 'tall/short or middle?'. However, this was not representative of a phenomenological interview and it felt uncomfortable. Prompts were used to try and illicit further responses, however the person often repeated what he had just said, gave another one-word answer or remain silent and smiled.

It was also unclear whether the participant remaining silent was a way of saying that he

did not want to answer the question or if it was his verbal comprehension not understanding this level of abstraction/reflection. For example, he found it very difficult to discuss more abstract concepts such as desirable personality traits in a potential partner or societal views on people with a learning disability having a relationship. He was able to provide more detailed information on more concrete questions such as what he likes to do with X (his girlfriend as a couple) and how they met.

At the end of the interview the participant felt one interview was enough and he did not want any subsequent interviews but he was happy for his data to be included in the research. This was concerning: had he found the pressure too great? There was a fear of under-performing as a researcher and there was a concern that he may have felt this as a participant or perhaps that he found the topic matter too personal.

This was the first interview and, despite practicing the interview guide on family and friends, it was an anxiety-provoking experience, which was increased by the staff discussion prior to the interview. A number of the interview questions could have been better phrased. There was also a concern that topics which could have been explored in more depth could have been overlooked and there were various instances which could have been followed up on. The issues encountered here are discussed extensively in the Learning Disability research literature and encountering some of these issues was expected but the severity was underestimated.

## **Themes**

**Despite the concerns discussed above there were some themes identified in the interview.**

**Caring** - He did mention caring for his girlfriend, holding her hand as she has mobility issues to stop her falling when out and making meals and tea for her. There was definite warmth and a traditional male role of caring for his lady, helping her on the bus etc. This was an area which could have been explored more.

**Loneliness** - When asked him what was life like before X and he said: 'Terrible'. He wanted a girlfriend but did not have one and he described himself as 'lonely'. When he met her it was, in his words, 'perfect and I am no longer lonely'. He told me he had lost his parents and did not speak with his brother and that he is happy now with her. This did make me wonder was it the person herself or the 'having a girlfriend' that was

important, as he was able to say very little about what were the benefits to being in a relationship in relation to X. Being asked by staff to now explore the past made it difficult to pursue this topic further.

**Physical side** - He did say he enjoyed kissing - the subject of a physical/sexual relationship was not pursued as it did not feel right at that time. This was not due to the researcher feeling uncomfortable with this topic but due to there being a lack of a bond between the participant and myself. It did not feel like we have developed a trusting relationship to discuss such sensitive issues.

**Attraction/ Physical Appearance** - He was able to say that he liked X because she was 'good looking'. He did say she was beautiful and had nice eyes but other than that he did not give any more detail.

**Social Status** - He also said that he liked people on the street to see him and her together and he thought she was good looking. I asked if he thought other people thought this too- he said he did not know (this is what he said when he didn't understand, I think).

**Societal Norms** - He said he 'did not care' if his partner had a job as this was not important. This is in contrast to a number of research articles on partner selection but he also wanted marriage and children (but not yet). This reflected a desire for a traditional family role.

### **Impact on learning for subsequent interviews**

- **Importance of building the relationship** - I spent quite a long time with each person, no less than 30 minutes and up to an hour. In this time people told me a lot of valuable information that I will revisit hopefully in the interviews. I also spoke a bit about myself where I worked/lived, my journey etc. This made people more relaxed than before, where I did not spend as long.
- **Preparation from staff** - Unlike the first interview people seemed clear on what the research was about and recognised the information leaflet and had some questions. This meant we could go through it again but they already had had a chance for the information to settle in before this.



- **Use of Pictures** - McCarthy (1999) experienced this issue within her research and attempted to overcome this by asking her participants to draw pictures to act as a visual aid to facilitate discussion within interviews but these are not used in the analysis.

## Appendix 6 - Consent Form

- I have read and understand (or have had them read to me) the 'Information about the research' and the 'confidentiality' documents.

Please tick or make your own mark



- I understand that I can leave the research at any time and I do not have to give a reason. Any information collected about me will be destroyed after 7 years (this is what the law says).

Please tick or make your own mark



- I agree to take part in the research

Please tick or make your own mark



Name of Participant (in print) \_\_\_\_\_

Signature of Participant \_\_\_\_\_



Name of Researcher (in print) \_\_\_\_\_


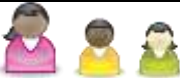


Signature of Researcher \_\_\_\_\_







Date \_\_\_\_\_

## Appendix 7 - Confidentiality (Easy Read)

### Confidentiality

<p><b>What is Confidentiality?</b></p>	<p>This is a word that means any information, from whatever source, should not be common knowledge</p> 
<p><b>For this research the confidential information would be:-</b></p>	<ul style="list-style-type: none"> <li>▪ Your name and the names of anyone else you speak about. </li> <li>▪ Your address, email or telephone numbers </li> <li>▪ The names of places you visit or use ( such as places of work, colleges, day centre or clubs)</li> <li>▪ Copy of the tape recording of you speaking to me </li> <li>▪ Written words of the things you said to me when I interviewed you.</li> </ul>

<p><b>How will this information be kept private?</b></p>	<p>All Information will be kept in a locked cabinet that only I have the key to.</p> <p>The computer I use will also have a special code so people will not be able to look at any information stored on here either.</p>  
--	---

<p><b>Where will an interview take place?</b></p>	<p>The interview will take place in a quite private room where you will feel comfortable and where no-one can hear what we are saying.</p>  
---	--

<p><b>What names will be used?</b></p>	<p>I won't use real names of people or places when I write up the research.</p>
--	---

<p><b>Will you tell people I know what I have said?</b></p>	<p><b>No</b> but if you tell me something that means you or someone else might be at risk of harm or abuse I would have to report it to someone whose job it would be to help you and others keep safe.</p>
---	---

<p><b>What happens to all the information when you have written your research report?</b></p>	<p>Once the research is done I will destroy all the information so no-one will see it.</p>
---	--

## Appendix 8 - REC Email

Dear Claire,

Thank you for your enquiry.

The Social Care REC reviews adult social care research study proposals from researchers based in England. It is part of the National Research Ethics Service, and its membership, expertise and procedures were developed to reflect the social care context.

The Social Care REC's aim is to complement other RECs by addressing gaps in provision, and taking on specialist roles. University RECs will continue to review social care proposals where appropriate: student research should normally be channelled through University RECs with the exceptions of:

- social care studies that are covered by the Mental Capacity Act, (MCA) where ethical approval by an 'appropriate body' – recognised by the Secretary of State for the purpose – is a legal requirement. The Social Care REC is an 'appropriate body' – recognised by the Secretary of State. University RECs are not 'appropriate bodies' and cannot therefore review research invoking the MCA.
- social care studies funded by the Department of Health. Ethical review by the Social Care REC is a funding requirement.

From your research outline it appears that you will not be including anybody who lacks the capacity to consent and would therefore not invoke the MCA. If this is the case, review by your University REC should be sufficient. However, if this is not the case, the Social Care REC would be happy to accept this for review.

Please contact me again if you need any more advice.

Best wishes

Barbara

Barbara Cuddon | Social Care Research Ethics Committee Coordinator | Social Care Institute for Excellence | T: 020 7089 6840 | Textphone: 020 7089 6893 | F: 020 7089

6841 | Direct Line: 020 7089 6899 | W: [www.scie.org.uk](http://www.scie.org.uk) | Goldings House, 2 Hay's Lane, London, SE1 2HB

[Barbara.Cuddon@scie.org.uk](mailto:Barbara.Cuddon@scie.org.uk)

Social Care Research Ethics Committee Website: [www.screc.org.uk](http://www.screc.org.uk)

SCIE is a charity registered in England and Wales Reg. No. 1092778, Company Reg. No. 4289790

Email Disclaimer : <http://www.scie.org.uk/email.htm>

## Appendix 9 - Information about the research (Participants)

My Name is Claire Bates.

I am a student at London South Bank University.

My telephone number is - 020 7261 4122

And my Email- [Claire.bates@choicesupport.org.uk](mailto:Claire.bates@choicesupport.org.uk)

<b>What is the research about?</b>	<p>I would like to talk to you about relationships with partners.</p> <p>I want to find out what you look for when choosing a partner</p>
<b>Why is this research important?</b>	<p>I want to find out about relationships people who have a learning disability have.</p> <p>I want to find out what makes some relationships successful and others not.</p> <p>I might also be able to find out from you what stops people who have a learning disability from having relationships.</p> <p>The results could be useful for you and other people who have learning disabilities who want a relationship with a partner.</p> <p>The results could also help staff support individuals with their relationships.</p>
<b>Why I have been asked to take part?</b>	<p>I have asked the people who support you to ask you if they would like to take part because they know you have had a relationship.</p> <p>I only want to interview people who have experience of a relationship. Your supporters think you may be able to help me with my research.</p>

<p><b>What will happen?</b></p>	<p>If you take part I will talk with you in private and ask you some questions. We will meet at a place you choose. These meetings will be called interviews'</p> <p>Each interview will last about one hour. We might have up to four interviews. This is so I can get lots of helpful information for the research.</p> <p>I will pay for any travel costs that you have incurred to attend the interviews.</p> <p>I will ask questions about what you look for in a partner and about the relationships you have had with partners in your life so far.</p>
<p><b>What else should I know?</b></p>	<p>Some of the things we could talk about may be upsetting or could make you feel sad. If this happens and you need someone to talk to I will help you (or your support worker) to find some support such as a counselling service (if you want this)</p> <p>It is important that you think about this when choosing if you want to take part or not.</p>
<p><b>What will happen to the tapes/ written notes from the interview?</b></p>	<p>I will record the interview on tape. You do not have to tell me anything which you do not want to, and you can stop talking to me.</p> <p>Your name will not be used in the research. I might use some things that you said when I write the research but I will make sure that nobody will be able to tell that you said it.</p> <p>I will only tell people what you have told me if you said someone was hurting you or someone else has been hurt. I will tell you if I</p>



	<p>have to do this before I do it. If this someone is hurting you and you need someone to talk to I will help you (or your support worker) to find some support such as a counselling service (if you want this).</p>
<p><b>Leaving the research - what happens?</b></p>	<p>You can decide to leave the research at any time.</p> <p><b>This is ok.</b> If you decide to leave I will not use anything you have said. I will destroy your records by shredding them and destroying the tape so no-one else will see them.</p>
<p><b>What will happen when the research is finished?</b></p>	<p>The research will be written up and a copy will be given to the examination board at London South Bank University (LSBU). I will also publish it in a journal (this is a like a magazine which anyone can read). As I said above no-one will know it is written about you.</p> <p>I will also produce an easy read summary of the research, which you will have a copy of.</p>
<p><b>Ethical Approval</b></p>	<p>This research has been approved by an ethics committee.</p> <p>This is an independent group of people who decide if the research is ok and protects the dignity, rights, safety and wellbeing of the people who take part.</p> <p>This means that they think that it is safe for people to take part in this study.</p>
<p><b>Taking part and not being happy</b></p>	<p>If you are unhappy about anything which takes place during the research or would like to make a complaint or talk to my main</p>

supervisor please contact-

Prof. Keith Popple

[popplekj@lsbu.ac.uk](mailto:popplekj@lsbu.ac.uk)

020 7815 8436

## **Appendix 10 – Participants' Stories**

### **Alan's Story**

Alan was a man in his 60's who lived in a supported living house with his wife and one other person in a small coastal town. Little was known about his early life. He had lived in care for some time, initially in a large care home. Alan liked the company of others and remained a sociable man. Alan enjoyed spending time with his wife's family and felt 'meeting people' was a highlight of marriage. Alan liked to travel, especially for its social aspect: he placed a great emphasis on his ability to go out. Alan had been married to Ann for about six years, meeting within the large care home: their relationship developed through a shared interest of watching television. Neither person had previous partners. Staff encouraged and supported their relationship and took an active role in its development. Despite staff encouragement, Alan said the decision to get married was his own but was unable to say why he wanted to. Alan had concerns about the success of the marriage initially but has a harmonious marriage with no arguments. Alan and his wife did not share a bedroom and had no desire to live alone as a couple. Alan was aware that in the future, due to Ann's mobility needs, she may have to move somewhere where she can be 'looked after'. There appeared to be no physical element to their relationship (although this was not explicit).

Alan and Ann used to enjoy days out alone together on public transport. However, due to her immobility, Ann was now unable to do this. Alan said this affected his marriage as he 'missed' his wife. Alan said he loved Ann and he knew this when she broke her hip (after they got married). This was due to the emotional impact it had on him. What he liked about Ann was she was 'always smiling'. The personality or attractiveness of a partner did not appear important to Alan, merely companionship.

### **Kerry and Dean's Story**

#### **Kerry**

Kerry was in her early thirties and had been with Dean for five years. Kerry's flat was in a small coastal town. She received minimal support from staff, was employed part-time and a member of an advocacy group. Kerry, due to financial reasons, did not want to live with Dean. Kerry said she enjoyed living alone and was not lonely. However, she had a small social circle and no-one else she loved.

Kerry had a complicated family background, being in care since childhood and had lived in twelve foster homes. Her father sexually abused her as a child and her step father physically assaulted her. She was also psychologically abused by him by isolating her from family life. It was suggested that Kerry's mother also had some form of learning disability. Kerry was unsure if charges were ever pressed against either her father or stepfather or if either were still alive. She used to receive upsetting letters which have now ceased. Kerry used to live in a care home where her ability to have overnight guests was prohibited. She claimed to have had numerous sexual partners but did not provide a number. She felt men in the past had 'let her down'. She had an ex-partner who 'pressured her' to do things of a sexual nature and was controlling. Kerry said Dean was good and looked after her. She had a minor physical impairment and Dean helped her with practical things such as shopping. She found his company the most rewarding element of the relationship. Kerry confirmed she and Dean engaged in a sexual relationship, claiming they have sex 'sometimes' but was not enthusiastic.

### **Dean**

Dean lived in a flat close to Kerry and only had minimal support from staff. Dean was raised by an adopted family with whom he remained close. Staff said he had a 'difficult past and fabricated stories to compensate this'. Dean had previous partners including a partner called Amanda who was 'mentally unstable' and abusive and he had a restraining order against her. Kerry confirmed this information. Dean was in a relationship with Amanda when he met Kerry but was unhappy as she was violent towards him. Dean had four young female children from another previous relationship: he had limited contact with them and Kerry had never met them. Despite this Dean was keen to have a child with Kerry. It was unclear if the children have a disability. Dean's sister looks after them and also supports the mother.

### **Their relationship**

Dean was physically attracted to Kerry and wanted to get married. Kerry liked to call Dean her fiancé but did not feel ready for marriage. However, he said Kerry was 'the first proper woman I've ever been with for, you know, for five years and I have stuck it out', suggesting that he had not been as committed to his previous relationships. Both enjoyed the companionship of the relationship and participation in shared interests. Dean said emotionally they were 'strong' but admitted to jealousy with regards to her male friends. Dean also enjoyed the material aspects of their relationship such as

sharing resources and Kerry buying him gifts. To Dean giving material goods or money appeared a way of showing that someone was important or loved.

## **John and Caroline's Story**

John was in his mid-fifties and Caroline was in her late fifties. Both lived in a registered care home with approximately six people in a village close to a coastal town. The other people at the property appeared to have much higher support needs than them. John had some health issues and now used a motorised scooter outside.

### **Caroline**

Caroline lived on a farm with her family as a child. Caroline's father died when she was young but she spoke fondly of him, recalling how he made her feel 'special'. Caroline had three older sisters: two lived abroad and one lived relatively close. Caroline gave no indication that she and her mother had a close relationship or that she was still alive. Caroline felt neglected and unconnected to her family. Caroline's mother sent her to boarding school at a young age. Caroline had various jobs which she disliked. Her mother eventually sent her to live in a convent which she disliked due to its strict religious rules. Subsequently she moved into a religious care home with strict routines. Caroline moved to a second care home which she appeared to like more however she spoke of her sadness when staff had left and she lost touch with them. Caroline had no previous partners prior to John.

### **John**

John grew up in a children's home and had no memory of his birth family. John was adopted by a widow with an infant daughter when he was around four years old. He had an adopted brother (who also had learning disabilities). He had to leave his home when she became too ill to look after him in his early teens and from there he moved to various children's homes. John liked living in a 'family' and would like to again. John felt close to his family, especially his sister to whom he spoke often and enjoyed her physical affection (cuddles). John had an abusive relationship prior to Caroline with a woman who lived in the same house as him. According to John, staff were unhelpful and did not stop the abuse and the relationship ended as she moved away.

### **Their relationship**

Caroline said it was 'sort of' love at first sight when she saw John. They met at a disco at home organised by staff. John initiated the relationship and asked her to be his girlfriend. Caroline recalls them sitting in the camper van and holding hands. Their relationship developed overtime with trips in the local area to cafés and lying on their beds watching TV. Caroline described this early period as when they were 'really in love' but their relationship became more of a close friendship as John no longer wanted to participate in the physical aspect of their relationship such as kissing. However, both claimed to love the other. The couple used to share a room and bed but John moved from their shared flat to separate rooms. Caroline said she was happy with this arrangement. They both enjoyed the companionship as they had few friends and they defined each other as 'best friends'. Caroline would like to get married but John did not want this yet.

### **Emma and Liam's Story**

Emma and Liam lived together in a registered care home with three other young people (under 35 years old) in a coastal town; Liam was in his early twenties and Emma was in her early thirties. Both said the age gap was not an issue and both were able to go out independently.

#### **Emma**

Emma lived at home with her family for most of her life, her parents were still together and she defined her family as affectionate. Emma and her parents had a close relationship. Emma experienced a period of poor mental health (as a consequence of being sexually assaulted) and was hospitalised then subsequently moved to her current home. She wanted to come home but her parents felt it was best she lived here as they felt it would be less likely that she would become ill again. Emma had two boyfriends prior to Liam. Her first partner abused her financially and psychologically and her staff supported her to end it. Emma's subsequent partner tried to (or may have actually) sexually assaulted her. Emma did not believe the perpetrator ever faced charges despite police involvement.

#### **Liam**

Liam grew up living with his family. When Liam's mother and father divorced he and his younger sister lived with his mother, with whom he had a close relationship. Liam did

not have an easy relationship with his father, as he could be depressed and appeared negative towards him. Liam previously lived in a house where a housemate attempted to abuse him financially and intimidated him. Liam had partners prior to Emma and once dated a girl who used a wheelchair and an oxygen mask, which he found embarrassing. Liam mentioned a number of 'girlfriends' at college/school but Emma was the first he defined as serious. Liam was bullied by a boy at school but when he physically retaliated the bullying stopped. He was exposed to further bullying on a train where a girl (without a learning disability) cut off some of his hair. Liam alerted his father who called the police. There was another incident where Liam was robbed by a man in the pub for his phone. Liam had a speech impairment which could have made him more vulnerable to abuse from the public as it identified him as different.

### **Their relationship**

Emma and Liam had been together for a year. They met initially in their local college and both were attracted initially by the other's physical appearance. They met when Liam moved into the current property and he asked her out immediately. Their first date was at a local cinema. Liam and Emma planned to move out and live together. They spoke often about their future together, receiving minimal support from staff. The couple engaged in a sexual relationship but had no plans to start a family. This was not Emma's first sexual relationship but it was Liam's. Liam had proposed to Emma and both are keen to marry. Both Emma and Liam's respective families liked their partners and support the relationship. Both valued the companionship provided by the relationship, having someone to do things and to go places with, as well as the physical affection. They supported each other emotionally (comforting her when she cries) and practically (borrowing money). They found it hard to be apart and speak constantly when not together.

### **Carrie and Joe's Story**

Carrie and Joe were a married couple who lived in a shared, supported living house on a council estate on the outskirts of a large town with two other housemates. Joe was in his mid-twenties and Carrie was thirty and both had Down's syndrome. It was unclear if the house was staffed at night. Both people travelled independently via public transport and required minimal support.

## **Carrie**

Carrie lived at home with her parents. She was adopted and has no memory of her birth parents. Carrie had a large family of seven brothers and three sisters but she was only really close with one sister. Carrie's parents divorced and prior to this frequently argued. Carrie was very close to her mother. Carrie had to move from home when her mother became terminally ill: it was not her choice but she understood why. Carrie's mother passed away recently and was happy to see Carrie settled before she died. Carrie claimed to have been 'almost raped' by an ex-partner prior to marrying Joe.

## **Joe**

Joe also spent his childhood and teenage years living at home with his family. Joe decided to move away from home. He moved from the first place he lived as he was unhappy with another resident and the staff, who invaded his privacy. Joe defined himself as a 'grandson of my granddad'. He was close to his granddad and saw him as a role model in regards to his strong marriage. Joe had a close relationship with his older brother to whom he frequently confided on sensitive topics like relationships for advice.

## **Their relationship**

The couple met in secondary school. Joe was too shy to ask Carrie out initially and they first kissed in the school shed. Joe asked Carrie on a date and they went to the cinema and became a couple soon after. They split up when school ended as they both went to different colleges and found it hard to continue the relationship. They met again when Joe moved into his current house: they had not seen each other since school. Their relationship blossomed. Joe proposed to Carrie and they had a large church wedding which their family paid for. Joe referred to Carrie as his 'soul mate'. Both said physical affection was important to them but they did not have a fully sexual relationship or plan to have children. They had an active social life and enjoyed activities such as cinema, shopping and meals out. Carrie had three part-time jobs, one as an Avon representative; a receptionist and a representative at the YMCA. Joe worked as a gardener and a football coach. They had a good circle of friends including people who do not have learning disability.



## **Mary's Story**

Mary was a woman in her mid-forties of Asian descent and had Down's syndrome. She lived alone in a bedsit within a converted house. The property is staffed 24 hours a day and she was unable to go out independently. Mary received support daily in all aspects of her life. She had a volunteer job in a charity shop. Mary had been Gary's girlfriend for approximately four years. Gary lived in another shared supported living house run by the same provider close by. They saw each other about twice a week. Gary had limited verbal communication and as a result was not invited to take part in the research. Mary had a busy life, attending social clubs and the local college. Mary said she had lots of friends and she was not lonely. She regarded the staff as friends. Food was a re-occurring theme throughout the interviews and was important as she was on a diet and keen to lose weight.

Mary lived at home with her family until she was in her late thirties. Her mother had health issues and her father cared for both her and her mother. She had a brother who also had learning disabilities who had lived at home with her but he now also lives in a care home. Mary remained close to her brother, who visits regularly. Staff informed me that there were financial abuse issues regarding her parents and they limit the amount of money she takes home on visits. Mary visited her parents at the weekend but did not enjoy this as her parents were too busy, wanting them to visit her more instead. Mary preferred to live here in her own flat even though she did not initially decide to move.

She did not have a boyfriend until she left her family, who prohibited it. Gary was her first boyfriend. She and Gary first met in a local college, however, they met most frequently in a club for people with learning disabilities. Mary enjoyed having someone to spend nights out with, dance with, go to the cinema or for lunch out. Gary visited her flat but did not stay overnight and they did not have a sexual relationship but enjoyed to kiss and cuddle. Mary explained that sometimes she and Gary had communication issues.

## **Peter's Story**

Peter was a man in his mid-fifties: he had been married to his wife, who was approximately the same age, for around ten years. Peter now has no family contact as his close relatives have died. He lived with his parents but his mother died and his father re-married. Peter lived within the family home until his father died and his step-

mother no longer wanted him living with her. Peter's stepmother subsequently ceased contact with him, which he found hard to accept and understand. Peter has lived in supported accommodation for many years. However, he was unable to say how long and it was unclear if he had lived in larger care homes or any learning disability hospitals.

Peter and his wife lived in the same property as Mary but had a flat as opposed to a bedsit Peter was supported by staff at all times in the community except trips to a local café or church and received support within his home for living tasks on a daily basis. Peter had a small social circle with few close friends except his housemates and wife and the only activity he engaged in without her is when he worked one day a week as a cleaner in an office. Staff attempted to broaden Peter's social circle outside his marriage to reduce his dependence on his wife but were unsuccessful. Peter said this suited the couple as they did not 'get on each other's nerves' spending that much time together, however, it was unclear if his wife held this view. Peter had very limited structured activities which he attended despite staff encouragement. Peter had a severe stammer which made verbal communication challenging for him. It was unclear if this possibly affected his confidence in social situations in terms of making friends.

The couple met in a local day service for adults with learning disabilities; they had known each other for some time prior to getting married. She used to live across the road from Peter and was Peter's first and only girlfriend. However, Peter seemed unable to go into depth regarding the early stages of their relationship. It was unclear how their relationship developed and information about their 'dating' was unknown. Peter proposed and claimed he chose to do this without staff input. Peter appeared to value tradition, explaining that he proposed in the traditional way by asking her down on bended knee. The couple married in the local church near his home, which they still attend each Sunday. It was a small wedding. It was unclear who was present but, due to the small social circles of both Peter and his wife and lack of family contact, it was possible the guests mainly consisted of staff and some friends. Peter spoke of the day fondly and their wedding picture took pride of place. The couple had a honeymoon in Spain but were unable to travel alone so staff accompanied them. The marriage was never consummated as the couple do not have a sexual relationship. They share a bed and enjoy physical affection but this was limited to kissing and cuddling, which Peter seemed content with. Peter said his wife was a 'good' because she did things for him

like washing his back and he valued the support she provided to him. It was clear that Peter valued the relationship with his wife and was proud to be married.

His wife's family did not like Peter and was unhappy that they married (possibly due to some financial issues). Peter has limited contact with them and when they have visited they have been verbally and physically abusive to him on occasions and staff safeguard Peter by refusing them entry if he is home. During the course of the research Peter and his wife separated upon her request and Peter was upset and confused about the situation and wished for them to resume being a couple.