The Experiences of Service Users with a Learning Disability Living in Adult Placements

Karin Lewis

May 2015

Supervisors:
Professor Neil Frude
Dr Rosemary Jenkins
Dr Rachel Potter

ACKNOWLEDGEMENTS

ABSTRACT

Adult Placement offers people with a learning disability a highly flexible form of accommodation and person-centred support provided by individuals and families in the local community and enables an individual to share in the life of the Adult Placement carer. A limited amount of research has focused on the characteristics of carers, and the reasons why people become providers of such placements. There has been little focus in research on service users' experiences of Adult Placements. The aim of the present study was to explore the experiences of adults with learning disabilities living in long-term Adult Placements, drawing upon the perspectives of service users and carers.

Twelve participants (six service users and six carers) were recruited from two Adult Placement Schemes and took part in a semi-structured interview. Interpretative Phenomenological Analysis produced four superordinate themes from the participants' experiences: The Function of Adult Placements - as a different model of care offering an opportunity for an 'ordinary' life for service users; Characteristics of the Service User/ Carer Relationship – one that is differentiated from others and provides a 'secure base' and 'safe haven' for service users; "Family" – integration into the family, experiences of family dynamics, family changes and coping; and Personal and Professional Issues for Carers – their relationships with the teams, important factors for the carer role, rewards and benefits, and challenges and dilemmas.

The results highlight the meaning associated with Adult Placement for service users and relationships developed with carers were found to closely resemble attachments as they are conceptualised in adulthood. This study provides evidence from the service user perspective to support the view that Adult Placement carers fulfil the role of attachment figures for adults with learning disabilities. Findings are considered in relation to existing literature. Clinical and service implications are discussed and recommendations for future research are made.

CONTENTS

Chapter 1: Introduction

PART 3: THE LITERATURE

PART 4: RATIONALE, AIMS AND OBJECTIVES

Chapter 2: Methodology

Chapter 3: Results

Chapter 4: Discussion

LISTS OF TABLES AND FIGURES

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

CHAPTER 1 - INTRODUCTION

1.1. CHAPTER OVERVIEW

This research aims to provide an understanding of service users' lived experience of Adult Placements and to investigate the nature and significance of the relationships between adults with learning disabilities and Adult Placement carers. Specifically, the research aims to explore how relationships with carers may help to meet the attachment needs of people with learning disabilities and what meaning this has for service users. This chapter provides an account for the need for such a piece of research and is comprised of four parts.

Part 1 provides key definitions of terms used throughout the study and an overview of the criteria for, and prevalence of, learning disability. A history of the development of learning disability services and policy is outlined, and the key concepts of 'Normalisation' and 'Quality of Life' are introduced. A description of Adult Placement follows, outlining the model of care, policy context, and the roles and responsibilities of Adult Placement carers. The current study is particularly interested in the views of service users and this leads to consideration of the issues surrounding the importance and challenges associated with the involvement of people with learning disabilities in research. Part 2 presents the theoretical perspective relevant to the study focusing on the relational context and attachment theory. The importance of emotional attachments throughout the lifespan will be highlighted and literature in relation to adult attachments in the general population will be discussed prior to the application of attachment theory to people with learning disabilities. Part 3 begins with a discussion of the current research on Adult Placement and on the attachment needs of adults with learning disabilities. This is followed by a detailed systematic review of the literature concerning the application of attachment theory to adults with learning disabilities and their relationships with carers. Part 4 concludes the chapter summarising the rationale, aims and objectives of the study.

PART 1: SETTING THE SCENE

1.2. DEFINITION OF TERMS

1.2.1. Learning Disability

'*Learning Disability*' is a socially constructed term and its meaning and definition have changed over time (Hatton, 2012). The term '*learning disability*' is used to refer to the population under study in this research. Alternative terms exist for this population and are used interchangeably. '*Intellectual disability*' is the term adopted internationally, mostly in the academic literature, and commonly used in the USA and Canada. Others include, '*developmental disability*', '*learning difficulty*' (however, the use of this term is ambiguous because it can be used to describe specific learning difficulties such as dyslexia and dyspraxia), and terms such as '*mental handicap*' and '*mental retardation*' which are regarded as out of date and no longer acceptable. In the UK, the most commonly used term in the professional context, academic literature, and government legislation and policy is '*learning disability*' or '*people with a learning disability*'. This study uses the term '*learning disability*' in accordance with the guidance provided by the British Psychological Society (BPS, 2000).

1.2.2. Service User

The term *'service user'* will be used to refer to people with a learning disability accessing services, as this terminology is commonly used in practice. However, the researcher uses this term in the inclusive sense as advocated by service user organisations. The service users referred to in this study are not passive recipients of services but self-identifying and seen as a person first and foremost (Shaping Our Lives, 2003).

1.2.3. Carers

Carers' organisations also favour inclusive definitions (Levin, 2004). In this study, the term 'carer' is used to refer to service users' Adult Placement carers. An Adult Placement carer is defined as a person who provides care and support (which may include accommodation in the Adult Placement carer's home) for no more than three service users at any one time

(Social Care Institute for Excellence, SCIE, 2005). Adult Placement carers are members of 'Adult Placement schemes'. These schemes are regulated under the Care Standards Act 2000. They are managed by local councils with social services responsibilities, or independent (profit-making or non-profit-making) bodies who are responsible for recruiting, assessing, training and supporting Adult Placement carers. Adult Placement schemes receive referrals, match potential service users with carers, and monitor placements to ensure standards are met (Department of Health, DoH, 2003).

1.2.4. Adult Placement

Adult Placement offers people (predominantly those with a learning disability, but also older people and people with mental health needs) an alternative, highly flexible form of accommodation and person-centred support, which is provided by ordinary individuals or families (Adult Placement carers) in the local community. This enables individuals to share in the life of the Adult Placement carer (SCIE, 2005). The Department of Health national minimum standards for Adult Placement (2003) provide the range of definitions for the types of care and support available under this service model, which includes both long-term and respite care. Also referred to as 'Adult Family Placements' or 'Shared Lives', in this study the term 'Adult Placement' refers to long-term accommodation with care and support in the family home of an Adult Placement carer.

1.3.   LEARNING DISABILITY CRITERIA

In *Valuing People: A New Strategy for Learning Disability for the 21st Century*, the Department of Health (2001a, p.14) stipulated that a 'learning disability' includes the presence of:

- a significantly reduced ability to understand new or complex information to learn new skills (impaired intellectual functioning), as well as
- a reduced ability to cope independently (impaired social functioning), and that
- both of these impairments were acquired before adulthood

Similar definitions are described in Welsh policies such as *Fulfilling the Promises: Report of the Learning Disability Advisory Group* (Welsh Assembly Learning Disability Advisory Group,

2001). In more recent literature regarding classification, the term 'social functioning' is replaced with 'adaptive functioning', and is clarified in terms of everyday social and practical skills (American Association on Intellectual and Developmental Disabilities, AAIDD, 2010). Irrespective of the precise terminology, or the wording in various definitions, a person is considered to have a diagnosis of a learning disability when all three of the above criteria are met.

1.3.1. Impairment of Intellectual Functioning

Psychometric assessment remains the principle method for determining a person's level of intelligence. Using tests based on a normal distribution of general intelligence, significant impairment is defined as performance more than two standard deviations below the population mean (BPS, 2000). On the Wechsler Adult Intelligence Scale, Fourth Edition, (WAIS-IV, Wechsler, 2008), the mean is 100 and the standard deviation is 15. More than two standard deviations below the mean correspond to an Intelligence Quotient (IQ) of 69 or less.

1.3.2. Impairment of Adaptive/ Social Functioning

Adaptive/ Social functioning is concerned with a person's performance in coping on a day-to-day basis with the demands of his/ her environment and at a level that is consistent with a person's age and socio-cultural expectancies. It includes assessment in the areas of: communication, self-care, home living, social relationships, use of community resources, self-direction, functional academic skills, work, leisure, and health and safety. To meet diagnostic criteria for learning disability, an individual requires significant assistance to provide for his/her own survival and/ or with his/ her social and community adaptation (BPS, 2000).

1.3.3. Acquired Before Adulthood

To be considered to have a learning disability, a person's significant impairments of intellectual and adaptive/ social functioning must have been acquired before 18 years of age (BPS, 2000). This criterion distinguishes people with a learning disability from those with acquired brain injury in adulthood. Most learning disabilities are present at birth or have an onset in early childhood (Carnaby, 2005).

1.3.4. Systems of Sub-Classification

People with a learning disability vary significantly in the individual degree and nature of disability. Such heterogeneity has led to a number of systems of sub-classification. Within the clinical context, sub-classifications of *mild, moderate, severe and profound* 'mental retardation' are used in two main classification/ diagnostic manuals (*Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, American Psychiatric Association, 2013; *International Classification of Diseases, Tenth Edition*, World Health Organisation, 1992). These systems employ the same descriptive criteria; however, cited IQ ranges do not correspond exactly.

The British Psychological Society (BPS, 2000) recommends that decisions involving sub-classification of learning disability should make reference to both intellectual and adaptive/ social functioning using specific criteria. This is based on the two category sub-divisions within operational guidance (BPS, 1991). For intellectual functioning, '*significant* impairment' may be applied to individuals with an IQ of between 55-69, and '*severe* impairment' to individuals with an IQ of below 55. For adaptive/ social functioning, 'intermittent and limited' support is indicative of a *significant* impairment of adaptive/ social functioning; and 'extensive and pervasive' support is indicative of a *severe* impairment of adaptive/ social functioning.

1.4. ESTIMATED PREVALENCE OF LEARNING DISABILITY

It is estimated that approximately 1.5million people in the UK have a learning disability (Emerson *et al*. 2012). However, accurate estimation of prevalence is not possible from large-scale population based surveys or from information held by central government departments (Emerson & Hatton, 2008). Many epidemiological studies of learning disability have typically used IQ assessments to classify a person as having a mild or severe learning disability, rather than using a combination of IQ and adaptive behaviour assessments recommended in current classification systems as described above (Welsh Assembly Learning Disability Advisory Group, 2001). Furthermore, in Wales, published up-to-date figures of the total number of adults with learning disabilities reflect only those receiving a service (Welsh Assembly Government, WAG, 2011).

The extent of the occurrence of learning disability also varies between localities and over time due to variation in the factors which influence causes of learning disability. Upward pressures on the incidence of learning disability include: increases in maternal age; increased survival of infants due to improvements in pre- and post-natal care; and, most notably, increased life expectancy. Downward pressures include: the impact of prenatal screening for Down's syndrome and improved health care and support resulting in fewer 'at risk' infants developing learning disabilities (WAG, 2007).

Information on the characteristics of people with learning disabilities, the services and supports they use and their carers is collected by several government departments and made publically available through a number of diverse channels (Emerson *et al.* 2012). Emerson and Hatton (2008; 2011) have published estimates of the need for social care support among people with learning disabilities in England which suggest sustained growth in the need for social care services. Adults with learning disabilities most commonly live permanently with family or friends (Emerson *et al*. 2012), but the combination of a variety of influential factors is likely to reduce the capacity of informal support networks to provide care. Such factors include: the increase in lone parent families; increasing rates of maternal employment; increases in the percentage of older people with learning disabilities (whose parents are unable to continue to provide care); and changing expectations among families regarding the person's right to an independent life (Emerson & Hatton, 2011). A subsequent shift to more formalised systems of care is likely to arise.

1.5. SERVICE PROVISION

How people with learning disabilities are viewed in society has changed over time. These changes are underpinned by societal and cultural values towards this group of people. Such values have also informed services that support people with learning disabilities and influenced how support is provided. One major change is the shift from institutionalised care to the provision of 'ordinary' community living. Early institutionalised care served as a means of containing people who were seen as worthless and unable to contribute to a productive industrialised society. The realisation that even those with profound and severe learning disabilities have the right to as normal a life as possible shifted the focus of care

from security, protection and uniformity to an individualised approach which aims to put the person with a learning disability, their needs and skills at the centre of any support provided (Carnaby, 2007).

1.5.1. Development of Learning Disability Services and Policy

The changes to service provision from institutionalised to community settings for people with learning disabilities has led to developments in new types of respite and short and long term care for individuals with a learning disability. In the UK, this has been supported by relevant policies and government legislation such as The Community Care Act (1990) and the 'Valuing People' White Paper (DoH, 2001a) which recognised the need for people with learning disabilities to lead fulfilling lives and to receive help from high quality services. The 'Valuing People' document introduces four key principles related to people with learning disabilities: rights, independence, choice and inclusion. An updated version 'Valuing People Now' continues to work on these principles (DoH, 2009).

In Wales, the All Wales Strategy for the Development of Services for 'mentally handicapped' people (Welsh Office, 1983) promoted ordinary lifestyles for people with learning disabilities and recognised the rights for broad ranging support based on individual needs (Todd *et al.,* 2000). Service development in Wales was also influenced by 'Fulfilling the Promises' (Welsh Assembly Learning Disability Advisory Group, 2001) which set out a vision for services for people with learning disabilities.

In the UK, the provision of community care has itself evolved considerably, with the development of different service models. Initially, homes of 25-30 people replaced larger institutions. The number of people within each home has reduced over time to seven or eight people and two or three in newer homes (Mansell, 1996). Such homes were based on an 'ordinary' life service model aiming to provide more fulfilling lifestyles for people with learning disabilities (King's Fund, 1980). The development of community services has relied upon guidance from a number of key ideas including the concept of normalisation and the notion of quality of life.

1.5.2. The Concept of 'Normalisation'

In Britain, the idea of normalisation has heavily influenced services supporting people with learning disabilities. Built on an underlying theme of campaigning for the equality of human and legal rights for all citizens (Bank-Mikkelsen, 1980), the aim of normalisation was to:

> *"[make] available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society"* (Nirje, 1980)

In practice, normalisation requires that people with learning disabilities are enabled to experience the 'norms' of everyday life, that they pass through the lifecycle, have rights to form relationships, and experience an acceptable standard of living.

The popularity of normalisation has been international, but its interpretation has been somewhat geographically defined (Culham & Nind, 2003). For example, in the USA, Wolfensberger (1972) developed the idea of normalisation further and initiated important changes to the approach. Referencing the way society views and represents people with learning disabilities and emphasising socially valued roles, normalisation became a way of encouraging services to create a positive image for people with learning disabilities, decreasing stigmatisation and increasing acceptance by wider society (Carnaby, 2007). In Britain, investigations into the living conditions of long-stay institutions enabled normalisation to influence the design of new service provision. Interpretations of normalisation in Britain tend to use O'Brien's five service accomplishments to inform and shape services (O'Brien & Tyne, 1981):

1. **Community Presence:** ensuring that service users are present in the same parts of the community as people without learning disabilities, be it at work or recreational activity;
2. **Choice:** supporting people in making choices about their lives in as many areas, and including as many issues, as possible;
3. **Competence:** encouraging the development of skills and abilities that are meaningful to the immediate culture, skills that decrease a person's dependency and are valued by non-disabled people;

4. **Respect:** increasing the respect given to service users by other members of the community by ensuring that the lifestyles of people with learning disabilities encourage positive images to be conveyed to others;

5. **Participation:** supporting people with learning disabilities in sustaining relationships with members of their family, as well as forming new relationships with others.

The concept of normalisation has received criticism based on the dangers inherent within an unquestioning value attached to cultural norms and the determination that devalued people should aspire to them (Chappell, 1997). Such criticisms highlight that social norms are not 'neutral', but are products of the society that constructs them. Furthermore, Whitehead (1992) and Oliver (1994) highlight the fact that, despite the influence of normalisation on professionals, it has not been adopted as a model for change by service users themselves. Brown and Smith (1992) suggest that normalisation should be considered as a starting point for change. Critical scrutiny of normalisation can be regarded as a positive step towards the social model of disability which assists people with learning disabilities in a struggle not only for better services, but also for full, economic, social and political inclusion in society (Chappell, 1997).

Hall (2010) argues that people with learning disabilities share with the rest of humanity a yearning to belong in relationships with other persons and/ or to a place or way of life. Clegg and Lansdall-Welfare (2010) argue that one major shortcoming of current policy is its failure to improve social relationships. The authors have published a number of service statements generated from local discussion that aim to enable service users, staff and commissioners to understand what services might offer and could develop. The statements propose that the creation and enhancement of relationships should lie at the heart of all a service does and that services provide a secure base for service users, carers and staff to explore the new. They should also address how people enter the service and how their needs are expressed. Needs should be brought together and attentive and collaborative support offered by staff in various roles and professions (Clegg and Lansdall-Welfare, 2010).

1.5.3. Quality of Life

The expansion of community provision has been paralleled by increased interest in the conceptualisation and measurement of quality of life (Perry & Felce, 2003). The term 'quality of life' is considered to encompass the breadth of life experience. It is a multidimensional construct that applies to the general population, not just to particular groups of people (Felce, 1997; Felce & Perry, 1999). It reflects a number of core life domains, such as emotional well-being, social well-being, material well-being, personal development, physical well-being, self-determination, and rights.

Results of comparisons of institutional and community care show that any model of community care provides better quality of care and, therefore a better quality of life, than institutional care (Emerson *et al.,* 2001, Perry & Felce, 2003). However, community residential provision does not guarantee a better quality of care and quality of life (McVilly *et al.*, 2006; Jackson, 2011). Although difficult to measure, there appears a general consensus that smaller group homes have a more positive impact on the quality of life for individuals with a learning disability (McConkey, 2007). However, most research has reported on resident outcomes in terms of the objective life conditions which residents experience. For a variety of reasons, evidence of service users' subjective experiences of their residential living situation is sparse (Perry and Felce, 2003). Forrester-Jones *et al.* (2006) found that 12 years after leaving hospital most people with learning disabilities remained socially isolated, with staff continuing to be the main providers of emotional and practical support. Clegg and Lansdall-Welfare (2010) suggest that one explanation for this concerns the orientation of services having been away from, not towards, relationships, which results in services seeking to promote autonomy and service users who are lonely and isolated.

1.5.4. Adult Placement

Adult Placement is one type of provision that has emerged following the shift from institutional to community settings within learning disability services and one that could be hypothesised to maximise the quality of life for the individuals they support. Adult Placement offers people (predominantly those with a learning disability, but also older people and people with mental health needs) an alternative, unique, and highly flexible

form of accommodation and person-centred support. They are provided by individuals who share their ordinary homes, in an ordinary community, and also their lives with people with learning disabilities who need support to live more independently (Shared Lives Plus, 2013; Bernard 2004).

In 2013, Shared Lives Plus published data that reported 12 Adult Placement schemes in operation across Wales. This included the two schemes from which participants have been recruited for the current study. All details identifying the specific locality of these two schemes have been removed or edited to ensure anonymity of participants.

1.5.4.1. Model of Care

Adult Placement has its roots in fostering. Adult Placement carers, like foster carers, are self-employed and are required to share their daily life with the person placed with them (SCIE, 2005). For service users, central to the aims and objectives of the Adult Placement scheme are the following principles:

- To live a normal life in the community
- To share the daily life of the Adult Placement carer
- To stay well and keep safe through the use of key documents and processes (defined in the regulations and national minimum standards for Adult Placement schemes)

Adult Placement schemes are considerably cheaper than other forms of long-term care. The average net savings from a long-term Adult Placement arrangement per-person per year are £26,000 for people with learning disabilities and £8,000 for people with mental health needs (Social Finance and Community Catalysts, 2013). Compared to the national unit cost of residential care, the UK Adult Placement network, Shared Lives, propose that a saving of up to 60% can be delivered for people with learning disabilities (Shared Lives Plus, 2013). The current analysis does not take into account potential wider benefits of Adult Placements, which may be providing further cost savings. For example, case studies suggest that an Adult Placement can significantly reduce someone's need for other support, such as day care. Furthermore, it is considered an example of best practice in reducing social isolation and strengthening support in communities, as people are encouraged to become

part of a community and develop greater levels of independence from services (Shared Lives Plus, 2013).

1.5.4.2.   The Policy Context

In Wales, the Adult Placement model of care meets a number of strategic aims and goals envisaged by the Welsh Government and UK Government (Shared Lived Plus, 2013). Adult Placement supports the development of sustainable communities as set out in the Welsh Government's *One Wales, One Planet* strategy (WAG, 2009). The inclusion of service users in ordinary families normalises disability and reduces stigma and the delivery of responsive and person centred services are consistent with the Welsh Government's white paper *Sustainable Social Services for Wales: A Framework for Action* (Welsh Government, WG 2011).

The national minimum standards and regulatory framework within which Adult Placement schemes operate were established by the Care Standards Act (2000), and originally placed responsibility with the carer as the registered person to meet the requirements of regulation. However, concerns with regard to the burden placed on carers and subsequent loss of carers (Bernard, 2004) led to revised standards. This shifted the focus of registration and inspection to the schemes rather than to individual carers (Care and Social Services Inspectorate Wales, CSSIW, 2004). Current Adult Placement guidance is also provided by the SCIE and draws primarily on practitioner, user and organisational knowledge (SCIE, 2005).

1.5.4.3.   Role and Responsibilities of Carers

Adult Placement carers are recruited and approved through a rigorous assessment process which is itself subject to quality assurance by an independent panel (Shared Lives Plus, 2013). Adult Placement carers are characterised by their relationship with their scheme and service users (SCIE, 2005). A practice survey undertaken by the SCIE in 2005 found that the schemes involved in the survey emphasised the importance of Adult Placement carers as the resource upon which Adult Placement depends. The Adult Placement carers interviewed as part of the practice survey spoke of helping the person placed with them to

change, grow, develop, and become more independent. They were also found to be most motivated by 'giving' and 'caring' (SCIE, 2005).

National minimum standards state that the Adult Placement scheme selection, procedure and training programme should ensure that carers have the competencies and qualities to carry out the tasks required to meet the person's needs (CSSIW, 2004). The introduction of national minimum standards for Adult Placement led to changes in the roles and requirements of Adult Placement carers. Carers are now required to demonstrate they have the skills and experience necessary to do their work, and they are expected to participate in on-going training and learning designed to ensure that they continue to work effectively with the people placed with them. They are subject to regular support and monitoring visits and to annual reviews of their work. For carers already established prior to the introduction of the national minimum standards, such changes in what is expected of them may have been a difficult concept that needed to be negotiated. Having provided valuable placements for a number of years, Adult Placement schemes have needed to support carers through the transition (SCIE, 2005).

The history of residential services suggests that the emotional development of people with learning disabilities living within institutions were not assisted by the setting (Clegg & Lansdall-Welfare, 1995). Service developments towards smaller residential homes have increased staff stability (Allen *et al*., 1990) which provides greater opportunity for individuals to work on emotional development and relationship-building. However, this also puts staff under greater pressure to work at a personal level (Clegg & Lansdall-Welfare, 1995).

There is an expectation in Adult Placement that carers will provide a safe and loving environment, a role that requires a significant level of flexibility, understanding and insight into the needs of the service user, and the ability to put the knowledge into action (SCIE, 2005). Reinders (2009) recognised the importance of the dyadic nature of caregiving, and emphasised the interpersonal relationship that develops between service user and carer as the vehicle to facilitate knowledge and skills of working with an individual. The quality of such a relationship and support depends on being attached and attuned to the

particularities of the service user. Support from the Adult Placement scheme, therefore, becomes essential for the carers to provide continuing effective support for the service user.

Adult Placement schemes provide a variety of training both mandatory and placement specific. Mandatory training includes topics such as Protection of Vulnerable Adults (POVA) Level 2, food hygiene, Mental Capacity Act, and Fundamentals of Care training which focuses on the value base and understanding good practices in relation to duty of care, the role of the care worker, equality and inclusion, person-centred approaches, communication and handling information. Training tailored to placements in relation to service users' identified needs can include training on dementia, autism, epilepsy, positive behaviour management, mental health, sensory impairment, learning disabilities, and bereavement. This is not an exhaustive list as schemes can offer access to a broad range of training depending on the circumstances. One Adult Placement scheme involved in this study had provided some training to Adult Placement carers about human development, attachment and the carer's role. This was provided by psychology within the associated health team. Unfortunately, a limitation of the current study is that it is not known if the carer participants who took part in the current study had attended this training session.

1.6. INVOLVEMENT OF SERVICE USERS WITH LEARNING DISABILITIES IN RESEARCH

Historically, people with learning disabilities have been excluded from participating in research, protecting them as a vulnerable population. Challenges to this perspective have promoted supporting individuals with learning disabilities to engage in research which is meaningful to their lives (Crook *et al.,* 2015). There are now many examples of people with learning disabilities being involved in research both as participants and as part of the research team (e.g. Boxall & Ralph, 2011; Abell *et al*., 2007).

Promotion of service user involvement is now part of mainstream policy agenda in health and social care (DoH, 2009; Royal College of Psychiatrists, 2003). Furthermore, the inclusion of service users in research has been widely advocated in order to ensure that service development is informed by service users' views (DoH, 2001a). One outcome of the social

model of disability and the 'nothing about us without us' movement (DoH, 2001b) is the adoption of an 'inclusive research' approach (Strnadová & Cumming, 2013) which is the term used to describe the diverse means of conducting research *with* people with learning disabilities. Walmsley and Johnson (2003) use the term 'inclusive research' to describe research based on the principles that research must:

- Address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them;

- Access and represent their views and experiences; and

- Reflect the fact that people with learning disabilities need to be treated with respect by the research community.

The expansive vision and potential broad application of the above principles is argued to be necessary for the sustainability of inclusive research, protecting against what is intended to be inclusive becoming exclusive and segregated from the wider research community (Nind & Vinha, 2012). Despite the policy requirement of user involvement there is a dearth of research which examines the extent to which service users are included in evaluating their own care (Young & Chesson, 2006).

1.6.1. Challenges and Overcoming Barriers

Service user involvement in research is met by a number of challenges including: negative staff perceptions of service user contributions; service culture surrounding risk management; beliefs about capacity to consent; the sense of agency and powerlessness; and communication difficulties or ability level (Crook *et al.,* 2015; Arscott *et al.,* 1998; Chaplin *et al.,* 2009; Gorfin & McGlaughlin, 2005). The involvement of staff and carers can support service users' expression of their views, but this may also introduce bias where service users are more inclined to offer responses that are deemed pleasing to staff (Young & Chesson, 2006). Acquiescence is more usually reported in relation to responses from people with learning disabilities and, therefore, needs to be considered as a potential obstacle for researchers (Rodgers, 1999; Sigelman *et al.,* 1981). Barriers for staff or carers in supporting service user involvement in research have also been identified including: lack of support within an organisation, lack of resources, and personal concerns about the research (Crook *et al.,* 2015). However, including others who know the service user well to act as 'proxy

researchers' to support engagement, build rapport and ensure informed consent is obtained can also contribute significantly to the achievement of service user inclusion (Nind, 2008; Walmsley & Johnson, 2003).

A number of studies have described techniques that can overcome some of the obstacles that may arise in the research process (Barr *et al.,* 2003; Gilbert, 2004; Nind, 2008). This includes developing means of enabling service users to give informed consent to participate in research and to engage in semi-structured interviews (Arscott, *et al.,* 1999; Walmsley & Johnson, 2003; Young & Chesson, 2006). Clear explanation of what the research will involve and using accessible information tailored to individual needs can help in overcoming the initial hurdle of enabling service users to give informed consent to take part (Chaplin *et al.,* 2009). Augmentative communication systems to supplement speech and pictorial support to assist receptive and expressive communication can also enhance service users' abilities to engage in semi-structured interviews (Arscott, *et al.,* 1999; Young & Chesson, 2006).

PART 2: ATTACHMENT AND LEARNING DISABILITY: THE THEORETICAL PERSPECTIVE

1.7. THE RELATIONAL CONTEXT AND ATTACHMENT THEORY

In line with social constructionist thinking, systemic approaches propose that individuals are connected in relationships with one another and that experiences are constructed and understood in relation to reciprocal patterns of interactions and behaviours occurring within a given context (Baum, 2006; Freedman, 2001; Vetere & Dallos, 2003). Attachment theory emphasises the influence of relational factors upon experiences, in particular experiences of separation, loss and safety (Bowlby, 1969; 1979; 1980). This model may provide a useful lens through which service users' experiences of Adult Placement and their relationships with their carers can be understood. It is, therefore, used to make sense of the results within the current study to provide a psychological understanding of the service users' and carers' experiences. Lynggaard (2005) suggests that as some adults with a learning disability have significant dependences on support staff to meet their physical, social and emotional

needs, these relationships may be particularly important. These might therefore be conceptualised as attachment relationships for service users. The nature of relationships between service users and carers in the current study will be considered from an attachment perspective.

An overview of attachment theory is initially presented and core constructs are introduced. Attachment theory as it has been applied to adult relationships is then outlined and followed by criticisms of the approach. The clinical implications of attachment are summarised prior to a discussion of attachment theory as it has been applied to people with learning disabilities.

1.7.1. Overview of Attachment Theory

British child psychiatrist John Bowlby formulated his theory on attachment following observations of distressed children separated from parents and animal experimental work by Harry Harlow on social deprivation (Harlow, 1958). Bowlby (1951; 1979; 1982) asserted that forms of attachment behaviour and the bonds to which they lead are fundamental within the development of the person and are present and active throughout the life cycle. Attachment is defined as an intrinsic biological motivational system, with the underlying mechanism of guiding the establishment of emotional bonds and directing a predictable, sequenced response to separation from an attachment figure (Shear & Shair, 2005).

Bowlby (1982) proposed that the attachment behavioural system motivates a person to seek proximity to supportive others (attachment figures) in times of need. A tendency to seek protection from threats, and comfort when distressed, accomplishes basic regulatory functions and serves an evolutionary function that would have been essential for the survival of infants (Schuengel *et al.,* 2013). Attachment behaviour is defined by Bowlby (1979) as:

> *"Any form of behaviour that results in a person attaining or retaining proximity to some other differentiated and preferred individual, usually conceived as stronger and/ or wiser"* (p. 129)

1.7.1.1.   A secure base and safe haven

Within the attachment model and in addition to proximity seeking and separation distress, core defining features associated with the role of the caregiver include the *secure base* and *safe haven* (Bowlby, 1969; 1979)*.* Provision of a secure base by the carer leads the child to feel safe to practice autonomy, exploring and investigating the world around them, with the expectation that on their return they will be welcomed and nurtured by the carer. The secure base also provides a haven of safety to which the child can seek proximity for reassurance and comfort during times of threat or distress. A secure attachment develops if the carer is available when called upon and is responsive to the child's needs in an attentive, reliable and sensitive way.

1.7.1.2.   Attunement and Containment

Other key constructs of attachment theory include attunement and containment. The emotional nature of the attachment bond was described by Bowlby (1969) who speculated that attachment experiences are stored in the brain's emotional-processing limbic system. In the first two years of life an infant is reliant upon the caregiver to contain their level of arousal within a tolerable range, for example to provide stimulation when the infant is in a low arousal state and to soothe and modulate high arousal states such as distress. The early relationship between infant and caregiver, therefore, acts as an external system for the child's internal regulation of emotional states (Malekpour, 2007). This requires the caregiver to monitor and modulate their own emotional states in order to be attuned to and co-regulate with the infant. Attunement is defined as the intersubjective sharing of affect (Stern, 1985), and is instrumental for the child to develop skills in emotion recognition, understanding, regulation and containment, and to enable the child to learn agency and control in interactions and elicitation of care. The attachment bond is thought to be lessened as a result of poor attunement between child and caregiver, and in such circumstances the child's capacity to self-regulate and self-soothe is undermined (Golding, 2007).

1.7.1.3.   The Neurobiology of Attachment

The importance of early attachment processes has been supported by research on brain development that demonstrates the influence of the early socio-emotion environment on

the evolution of brain structures responsible for an individual's socio-emotional functioning for the rest of the life-span. In essence, the maturation of the adaptive-right brain regulatory capacities is dependent on the experience embedded within the attachment relationship between infant and caregiver. The experience can either positively or negatively influence the maturation of the brain structure and the psychological development of the infant (Schore, 1994).

1.7.1.4. Attachment Style

The early interpersonal experiences between infants and caregivers shape behavioural systems and consequently influence both child and adult mental representations of relationships (Bowlby, 1982). Individual differences in the experiences of caregiving have been found to lead to notable differences in patterns of attachment. Four attachment styles have been identified in research, each being associated with a corresponding parenting pattern (Salter Ainsworth *et al.,* 1978; Main & Solomon, 1986). A secure attachment style is associated with responsive caregiving; an insecure-avoidant attachment style with rejecting, rigid and hostile caregiving with a caregiver who is averse to contact; an insecure, anxious-ambivalent attachment style with insensitive, intrusive and/ or inconsistent caregiving; and a disorganised/ disoriented attachment style with a quality of caregiving that is helpless, frightened and lacking confidence.

The quality of caregiving relates to the core concepts in attachment theory as outlined above. The extent to which the caregiver is able to provide a secure base and safe haven, their ability to provide emotional containment and facilitate attunement can lead to the development of secure, insecure or disorganised patterns of attachment (Malekpour, 2007). According to Bowlby (1988), positive interactions promote the formation of attachment security - a sense that the world is safe, that attachment figures are responsive and sensitive, and that it is possible to explore the environment with curiosity and to engage effectively and enjoyably with others. Positive expectations about others are reflected in positive views of the self as competent and valued, a cognitive framework referred to by Bowlby (1969) as an internal working model that comprises mental representations for understanding the world, self and others.

An insecure pattern of attachment developed by an infant who has experienced insensitive caregiving is characteristic of strategies that have enabled the infant to feel safer within the relationship. However, such strategies become problematic as the infant matures, impacts on their ability to elicit care, and influences ways of relating to others in the future (Golding, 2007). An internal working model is formed where affect-regulation strategies are organised around negative beliefs such as worries about others' intentions and doubts about self-worth. Anxiety and avoidance strategies are adopted as a result. Internal working models have been demonstrated to be moderately stable across time assuming that early attachment representations are retained throughout development and have an ongoing effect on attachment dynamics throughout the lifespan. However, it is also acknowledged that early attachment representations may be revised and updated in light of ongoing experience and, therefore, may or may not correspond to attachment representations later in life (Fraley, 2002). The degree to which early attachment representations influence adult attachment patterns is unknown.

1.7.2. The Application of Attachment Theory to Adult Relationships

Although the attachment system appears most critical during the early years of life, Bowlby (1988) asserted that it is active over the entire lifespan and is manifested in thoughts and behaviours related to support seeking. He argued that even fully mature and autonomous adults benefit from seeking and receiving care from other people when threatened, in pain, lonely or demoralised. Adult attachment figures may be identified by four defining features: a desire to maintain proximity to a unique individual who is not interchangeable with any other; from whom separation is resisted; who can be turned to as a safe haven for security and comfort at times of distress; and who is representative of a secure base from which a person can freely interact with the world, take risks and explore the unknown (Ainsworth, 1989; Feeney, 2004; Hazan & Zeifinan, 1999).

Bartholomew and Horowitz (1991) developed a four-group model of adult attachment that incorporates internal working models of the self (representations of self-efficacy and self-value); and others (representations of attachment figure responses). These are combined to generate four adult attachment styles: secure; anxious-preoccupied; dismissive-avoidant; and fearful-avoidant (see Figure 1.1).

Figure 1.1: *Four-group Model of Adult Attachment (Bartholomew & Horowitz, 1991)*

MODEL OF SELF
(Anxiety)

		POSITIVE (Low Anxiety)	**NEGATIVE** (High Anxiety)
MODEL OF OTHER (Avoidance)	**POSITIVE** (Low Avoidance)	**SECURE** Comfortable with intimacy and autonomy	**PRECOCCUPIED** Overly Dependent/ 'Clingy'
	NEGATIVE (High Avoidance)	**DISMISSING** Counter-dependent – denial of need/ dependency	**FEARFUL** Socially Avoidant

Such adult attachment styles map onto the childhood attachment styles identified by Salter Ainsworth *et al.* (1978) and Main and Solomon (1986). According to Bartholomew and Horowitz (1991), the self and attachment figures are considered positive or negative i.e. the self as worthy or unworthy of love and attention; and attachment figures as available/ caring or rejecting. Additionally, the quality of attachment can be rated by considering the level of anxiety and avoidance associated with each category. For example, securely attached individuals experience low anxiety and low avoidance which results in being comfortable with intimacy and autonomy; and insecure-preoccupied individuals experience high anxiety and low avoidance resulting in overdependence, and so forth. There is a growing body of evidence confirming these attachment styles as reliably identifiable in the adult population (Shear & Shair, 2005).

A secure attachment style in adulthood reflects a history of warmth and responsive interaction and, as a result, individuals are accepting of both dependence and independence in a relationship. The other styles reveal insecure attachment traits: anxious-preoccupied adults seek high levels of approval and responsiveness; those described as dismissive-avoidant view others as less positive than themselves; and the fearful-avoidant style results

in little trust in a relationship and suppression of emotional experience (Watt & Brittle, 2008).

1.7.2.1. Types of Adult Attachment Relationships

Attachment theory in adulthood has most commonly been applied to romantic relationships. Hazan & Shaver (1987) demonstrated that romantic partners seek proximity to each other, feel comforted when their partner is present, or anxious and lonely when their partner is absent. On the basis of the parallels drawn, they concluded that the principles of attachment between infant and caregiver are fundamentally the same as those between romantic partners in adulthood, with the attachment figure providing a secure base. Other adult relationships have received less attention within the attachment literature, but Salter Ainsworth (1993) proposes a wide range of relationship partners who are potential attachment figures, including friends and siblings or context-specific attachment figures such as mentors or therapists. Attachment theory has also been applied to groups, institutions and symbolic figures, where an emotional connection and a sense of security to which individuals may seek proximity can be identified (Mikulincer & Shaver, 2007). Furthermore, although pets do not fulfil the typical safety features assumed by attachment theory, the devotion some people feel towards their pets, particularly dogs, in addition to characteristics such as being readily available, attuned and responsive to owners, suggests the existence of an attachment relationship (Sable, 2007).

1.7.2.2. Differentiating Attachment Relationships in Adulthood

An attachment relationship that exists between two people can be differentiated from other types of relationships by a history of one person directing attachment behaviour to a particular other person who tends to respond to the attachment behaviour (Schuengel *et al.,* 2013). Furthermore, attachment relationships entail mental representation in the internal organisation of an individual. Such relationships develop over time, are long-lasting, and serve a protective, restorative and developmental function above and beyond fun and companionship (Salter Ainsworth, 1993). Such relationships are differentiated from other types of close relationships. Attachment relationships are assumed between child and primary caregiver and may or may not develop between partners in long-term romantic relationships (Cassidy, 1999). Bowlby (1969; 1982) used the notion of an 'attachment bond'

to refer to the affective investment in an enduring relationship with a specific person, a stronger and wiser attachment figure that can provide a secure base and safe haven.

1.7.2.3. *Differentiating between Child and Adult Attachments*

One important distinction between infant/ child-caregiver attachments and adult attachments involves the degree of equalising or reciprocation of roles in the relationship. For example, within an adult attachment relationship between romantic partners, each individual at some point may look for comfort or support from the other, which is reciprocated through the provision of reassurance and care, and thus feelings of security. Each partner, therefore, can serve as an attachment figure for the relevant other and be temporarily stronger and wiser (Salter Ainsworth, 1993). This is, of course, different to an infant-caregiver relationship, where the caregiver provides but does not receive security (Rutter, 1995). The child does not serve as an attachment figure to the caregiver and the caregiver does not base their security within the relationship with the child. Should a reversal of roles occur within a child-caregiver dynamic, it leaves the child uncertain about their own secure base and safe haven which is likely to be detrimental to the development of a secure attachment style (Mikulincer & Shaver, 2007). This is described as a unidirectional form of attachment which is appropriate within the context of the child-caregiver relationship, examples of which may also exist in some forms of adult attachment relationships such as that between a client and therapist.

1.7.3. Criticisms of Attachment Theory

Critics of attachment theory vilify Bowlby for blaming mothers when children experience difficulties (Clegg & Lansdall-Welfare, 1995). Bowlby (1988) suggests that many criticisms of attachment theory have their origin in a culturally negative judgement of dependency. He maintains that attachment behaviour is appropriately displayed by people of all ages facing psychological or physical threats, and that to perceive dependent behaviour as childish is to misunderstand its role (Clegg & Lansdall-Welfare, 1995). Rather, care-seeking and care-giving are considered basic components of human nature and the ability to offer effective and sensitive care depends on the degree to which individuals have received it themselves (Bowlby, 1988). Emotional development throughout life in this context can be described as

moving along a continuum from immature to mature dependence, rather than towards independence (Holmes, 1993).

1.7.4. The Clinical Implications of Attachment

The presence and availability of attachment relationships throughout the lifespan fulfils a core human need, and the quality and security of attachment relationships have been shown to be vital for preserving mental health, emotional well-being and coping capacity. For example, securely attached children are more likely to be sociable and to show more adept emotional regulation (Greenberg, 1999). Furthermore, when attachment relationships are nurturing and secure, they promote the development of adults who are self-reliant, confident about their ability to love and be loved, and resilient in dealing with life's stresses and crises (Sable, 2007). In contrast, insecure attachment is related to difficulties in regulating emotions and relating to others. It is also associated with vulnerability to psychological distress, poorer mental health and behavioural problems in childhood, and lower resilience and increased risk of psychopathology in adulthood (Sable, 2007; Dozier *et al.,* 1999).

Specific types of dysfunctional adult attachment styles have been demonstrated in research to be related to mental health difficulties, personality disorders and adjustment to bereavement and loss. For example, individuals with secure attachment styles are found to experience less general anxiety, panic, social and simple phobia, agoraphobia, post-traumatic stress disorder, obsessive-compulsive disorder, psychosis, mania and depression when compared to those with dismissing and preoccupied styles (Cooper *et al.,* 1998; Mickelson *et al.,* 1997). Other research findings suggest personality disorders to be more severe manifestations of attachment disruptions and to be consistent with the defining characteristics of each classification (Allen *et al.,* 1998; Brennan *et al.,* 1998). In relation to bereavement and loss, Stroebe *et al.* (2005) concluded that securely attached individuals are unlikely to suffer complicated grief unless other risk factors are present, whereas those with insecure attachment patterns are more vulnerable to complicated grief.

1.7.5. People with Learning Disabilities and Attachment Theory

Within the learning disability population it is widely acknowledged that emotional problems are three to four times more prevalent than in the general population (Prosser, 1999;

McClure *et al*, 2009). Furthermore, people with learning disabilities may present with significant psychological difficulties which are complicated by limited capacity for solving problems and limited ability to adopt appropriate and effective coping mechanisms (Royal College of Psychiatrists, 2004). Considering the fact that research carried out in the general population suggests that the quality and security of attachment relationships is shown to preserve mental health, emotional well-being and coping capacity, it is surprising that little attention has been paid to the attachment needs and issues in adults with learning disabilities. That which is available is discussed in section 1.8.

1.7.5.1.   The Attachment Needs of People with Learning Disabilities

There are a number of personal and contextual factors known to impact on the lives of people with learning disabilities that raise particular implications for attachment within this population, including: emotional well-being and mental health issues; limited integration and personal relationships; and institutionalisation and residential care.

Hollins and Sinason (2000) suggest that the disruption in the early attachment processes may present a possible vulnerability factor for emotional difficulties in people with learning disabilities. Disruptions or irregular bonds may be more likely to occur due to a caregiver being unavailable or unresponsive, or due to a child's disability or temperament hindering their ability to form secure attachments with others. Such disruptions may potentially lead to increased feelings of anxiety and insecurity, impacting on future interactions with others, a person's self-esteem, and physical and emotional well-being (Watt & Brittle, 2008). It is difficult to ascertain a specific link between attachment style and the development of mental health issues within the learning disability population, but, such factors highlight the attachment needs of people with learning disabilities.

Despite the development of policy and services that have aimed to promote better lives for people with learning disabilities, as discussed in section 1.5, limited social integration and isolation continue to feature in the lives of people with learning disabilities. People with learning disabilities may have fewer relationships with peers and non-disabled people who are neither family or support staff, and already limited social networks become even smaller with age (Clegg & Lansdall-Welfare, 1995). People with learning disabilities also have

25

limited opportunity to develop intimate or sexual relationships, and those that do, are less likely to endure, due to additional barriers and constraints (McCarthy, 2005). It is apparent that for many adults with learning disabilities, opportunities to develop and maintain the types of close relationships and attachments deemed essential for psychological and emotional well-being throughout the lifespan are far more limited.

Relationship difficulties are likely to be more common due to the pattern of residential services provided in the past that have militated against emotional development (Clegg & Lansdall-Welfare, 1995). Janssen *et al.* (2002) recognise the disruption to the infant-caregiver attachment relationship as a result of institutionalisation. Other factors such as high staff turnover and small staff to client ratios have minimised the extent to which staff could be available and can act as responsive attachment figures able to meet the emotional needs of residents.

1.7.5.2. Attachment Relationships and Carers of People with Learning Disabilities

It is proposed that services can help to provide a secure base for individuals, thus alleviating anxiety (Gelder *et al.,* 2000). A sense of security and autonomy can be promoted via caregiving, and carers aim to meet the physical and/or psychological needs of people with learning disabilities, many of whom have histories of separation, abandonment and maltreatment (Watt & Brittle, 2008). Insecure attachment behaviours may contribute to the underlying functions of behaviours deemed challenging, such as social attention. They may also lead to what can be perceived as clinginess and overdependence on a particular carer, or anxiety responses when a carer is unavailable or unresponsive (Adshead, 1997). Feelings of anger may be evoked when someone's relationship with someone who represents an attachment figure is threatened (Watt & Brittle, 2008). Hall (2010) argues that people with learning disabilities share with the rest of humanity a yearning to belong in relationships with other persons, disabled as well as non-disabled. Clegg and Lansdall-Welfare (2010) argue that contemporary service provision should have the creation, enhancement or improvement of relationships at the heart of all the service does.

1.7.6. Conclusions

Psychological theory has been drawn upon to provide an attachment framework through which the relational context for people with learning disabilities can be understood. It is hoped that this theoretical perspective can provide a psychological understanding of the experiences of adults with a learning disability living in Adult Placements. Observing and understanding through an attachment lens emphasises the importance of relationships and provides a powerful and integral context that shapes the service user and carer relationship. The following section considers the relevant literature in relation to the current study including research pertaining to theoretical perspective of attachment.

PART 3: THE LITERATURE

1.8. OVERVIEW OF THE LITERATURE

To set the scene for the current study, key research on Adult Placement and, in particular, service users' views of Adult Placement, is described below. Due to the nature of the relationships developed between service users and Adult Placement carers, the literature relating to the attachment needs for adults with learning disabilities, and attachment relationships between service users and carers is discussed. A systematic review of the application of attachment theory to adults with learning disabilities and their relationships with carers provides a more detailed in-depth discussion of the most relevant research and examines the quality of the available studies.

1.8.1. Adult Placement Literature

Relatively little formal research and systematic evaluation on Adult Placements has been reported and this is especially true of people receiving a long-term placement. Dagnan (1997) applied a structure, process and outcome model to organise a review of evaluation of Adult Placement schemes. Previous research has looked mostly at the characteristics of those who provide long-term Adult Placements (Gage, 1995; McConkey *et al.,* 2005) or the recruitment and retention of providers (Bernard, 2004; Hanrahan, 2006). Joshua (2012) explored in-depth the experiences of individuals who provide Adult Placements for

individuals with a learning disability to explore the reasons why people become providers of such placements. The findings suggested that such carers are both highly motivated and committed to providing high quality care and that this in turn has a positive impact on the quality of life for individuals with a learning disability. These findings appear to support the suggestion that small community based support options are advantageous for individuals with a learning disability (Joshua, 2012). The author acknowledges that the study revealed a number of perceived benefits for the service users including the fact that many providers described a closeness that had developed in their relationships with service users. An area for future research, exploring the service user perspective in relation to these issues, was identified.

1.8.1.1. *Service Users' Views of Adult Placement*

There is very little formal research investigating Adult Placements that involves adults with learning disabilities. McConkey *et al.* (2004) studied short-term family placements for adults with learning disabilities who were living with older family of origin carers. They explored the experiences of older family carers, service users and individuals who provided short-term Adult Placements for the carers, including the benefits of such schemes. Within this research they interviewed 27 people with intellectual disabilities who were receiving short-term family placements, with a further 20 people in a contrast group. Service users gave a number of reasons for liking their placements. The most common were that the Adult Placement providers were nice, kind people and that it was an enjoyable experience for them. Placements were also evidenced to offer a wide range of activities which differed from those in their own home. Other benefits from the families' point of view were the enjoyment the individual with a learning disability had and the ability for them to meet new people. They also felt that the provider acted as an extended family for the service user. It is important to note that this research focussed on short-term placements for adults with learning disabilities, the experience of which may be very different from those of people who reside in long-term or permanent Adult Placements.

Benefits for service users of this model of care have been described in the Social Care literature and Social Services Inspectorate (SSI) inspection reports (SCIE, 2005). The views of people with learning disabilities in Adult Placements have also been gathered through the

use of user focus groups as part of an approach to defining and reviewing 'Best Value' in local authority and jointly commissioned services for people with learning disabilities (Cambridge & Michelle, 2001). Overall findings reported positive experiences of Adult Placements and a wish for them to continue. Service users talked about the family nature of their placements, and said that carers were 'kind' to them. Hirst (2000) provides anecdotal evidence from social workers of the benefits of a one-to-one caring relationship offered in Adult Placement.

1.8.2. The Attachment Needs of Adults with Learning Disabilities

Very few studies have examined attachment issues in adults with learning disabilities. Janssen *et al.* (2002) reviewed available studies and indicated that people with learning disabilities are at risk for developing insecure, especially disorganised, attachments and that a greater proportion of people with learning disabilities have insecure attachments compared to the general population. However, later research has suggested that secure and insecure attachment rates may be similar, at least for those with mild disabilities (Larson *et al.,* 2011).

Preliminary investigations have provided support for the reliability and validity of a third party observational measure to assess secure attachment style in adults with learning disabilities (Penketh *et al.,* 2014) and to study the relationships between attachment security, level of learning disability and challenging behaviour. However, a lack of reliable and validated assessment tools for identifying the attachment needs of adults with learning disabilities contributes to the difficulties in establishing rates of attachment styles in this population. Nevertheless, those who do have insecure attachment styles might find it more difficult to manage interpersonal relationships with carers. For example, individuals with anxious attachments may be hyper vigilant to rejection (Baldwin & Kay, 2003) and may therefore feel distressed when preferred carers support others.

Research has drawn upon attachment theory in the development of a semi-structured interview to investigate the personal attachment related experiences of adults with learning disabilities (Smith & McCarthy, 1996). However, the authors acknowledge the limitations of focusing on one particular component of attachment, namely comfort seeking, and ignoring

other important aspects of adult attachment relationships. Other research has focused on the presence of reactive attachment disorder (RAD) symptoms in adults with learning disabilities (Minnis *et al.*, 2010) demonstrating their presence in this population. Symptoms were associated with childhood adversity and not with ability level. However, the researchers acknowledge that data collection was necessarily retrospective and that no measure of reliability was possible for some data.

Further research with the adult population has focussed on the development of a stress-attachment model to provide an explanatory framework for the development of challenging behaviour among people with learning disabilities (Janssen *et al.*, 2002) and has investigated the relationship between challenging behaviour and insecure attachment (Clegg & Sheard, 2002). Janssen *et al.* (2002) suggest that security increases resilience to stress and should therefore be associated with less challenging behaviour. Clegg and Sheard (2002) found that overinvestment in a few relationships reflecting attachment insecurity was associated with challenging behaviour. On the other hand, Larsen *et al.* (2011) found that insecure attachment was unrelated to most forms of challenging behaviour. Thus, the current literature does not provide robust evidence for a relationship between attachment and challenging behaviour.

1.8.3. Attachment Relationships between Service Users and Carers

Care staff are widely recognised as providing one of the most important sources of support to people with learning disabilities and their families (Test *et al.*, 2004). However, very little research has focussed specifically on the type of relationship that develops between care staff and the service users they support. The quality of care given to people with learning disabilities is highly dependent on the staff who provide it (Hall & Hall, 2002) and it has been suggested that while paid care staff may view some interactions as a functional requirement of their job, people with learning disabilities may attach more significance to them, not least because these are the people with whom they spend most of their time (Pockney, 2006).

Circumstances that activate caregiving, for example, when seeking comfort at times of danger or distress or when requiring help to gain from a learning opportunity frequently arise for people with learning disabilities. It is therefore likely that attachment dynamics

between adults with learning disabilities and their carers would be observed (Mellows, 2012). Lynggaard (2005) suggests that as some adults with a learning disability depend significantly on support staff to meet their physical, social and emotional needs, these relationships may be particularly important. It may therefore be considered that these could be conceptualised as attachment relationships for service users. Kerr (2007) highlighted the fact that the nature of the role that care staff provide can lead to the development of close attachments between care staff and people with a learning disability, particularly as it is often the case that care staff have known the service users they support for many years. Mattison and Pistrang (2000) revealed the immense pain of separation and loss experienced by service users when a key worker leaves, and showed that, in particular, abrupt endings often result in feelings of abandonment and wrongdoing. Staff participants in this study showed a clear awareness of how much they meant to service users on a personal level, and described strong attachments that they themselves had formed toward service users. Many staff described the sense of reciprocity and mutual pleasure in their relationships with residents, although at times they expressed feeling uncomfortable and overwhelmed by the service users' high levels of emotional dependency on them.

Members of staff or carers are key figures in the lives of people with learning disabilities, particularly in long-term settings. Carers are required to combine compassion and support with understanding, and to be responsive to an individual's needs. It is not an easy task to manage the interpersonal complexities of relationships which require the setting and maintenance of boundaries to ensure that a relationship remains therapeutic in consistency, predictability and structure (Watt & Brittle, 2008). Of course, carers also have their own psychological needs and attachment styles which may impact on the quality of their relationships with service users.

In the first study of its kind, Stimpson (2009) investigated in-depth the relationships between adults with learning disabilities and support staff in a residential support setting. This study found that such relationships closely resemble attachments as they are conceptualised in adulthood, and provided evidence in favour of the view that support staff represent attachment figures for people with learning disabilities living in a supported residential context. The service users in this study distinguished the relationship from any

other in their lives, and identified the staff member as holding a special status which in some cases was comparable to their relationships with a family member. Such findings are similar to those from research undertaken in children's services where staff members view themselves as a 'surrogate' family for service users (Moses, 2000). However, the findings suggested that the nature of the attachment bond is unidirectional in that staff appear to serve as attachment figures for service users, while this is not reciprocated. This is considered important in theoretical terms, as it is consistent with how attachment is conceptualised within professional relationships (Salter Ainsworth, 1993) and thus distinguishes this form of attachment relationship from attachment within the context of personal or intimate relationships (Stimpson, 2009).

Due to the type of provision of Adult Placements, they are more akin to fostering within children's services. Adult Placement carers spend far more time with the service users they support and are encouraged to treat them as 'extended family' (DoH, 2012). It may, therefore, be possible to consider Stimpson's findings in the context of Adult Placements and to consider whether relationships between Adult Placement carers and service users transcend the professional context into a personal one, considering the family context in which the person resides. Exploring how service users experience relationships with Adult Placement carers and considering such relationships within the context of attachment theory may provide further understanding of the needs of people with learning disabilities.

1.9.   A SYSTEMATIC REVIEW OF THE APPLICATION OF ATTACHMENT THEORY TO ADULTS WITH LEARNING DISABILITIES AND THEIR RELATIONSHIPS WITH CARERS

1.9.1. Introduction

The current study aimed to understand service users' experiences of Adult Placements and their relationships with their carers. An initial literature search and review was carried out at the point of proposal of the study. Following completion of the data collection and analysis, a more comprehensive literature search was completed to identify the literature relevant to the themes that had been identified from the analysis, and which would inform the literature included in this section, the systematic review and discussion of the research.

The question for the systematic review was:

How can attachment theory contribute to understanding attachment issues in adults with learning disabilities and their relationships with their carers?

The aim of this review was to critically evaluate the current literature using a formal framework. The process and outcome of the systematic review is described in the following sections that outline: the search strategy (section 1.9.2); search terms (section 1.9.3); and the inclusion criteria and exclusion criteria used to identify relevant studies (section 1.9.4). An overview of the studies introduces those included in the review (section 1.9.5), and the framework used for assessing the quality of the key studies is presented (section 1.9.6). A narrative of the quality review outlines the results (section 1.9.7) and discusses methodological issues. Finally, a synthesis of the findings integrates the results of the review with the wider literature and current project (section 1.9.8).

1.9.2. Search Strategy

Six electronic databases were searched on 5th April 2015 using the OVIDSP platform to identify relevant studies:

- AMED (Allied and Complementary Medicine)
- EMBASE (Excerpta Medica Database) 1947-Present
- HMIC (Health Management Information Consortium)
- Ovid MEDLINE(R) 1946-Present
- PsycINFO 1806-Present
- PsycARTICLES Full Text

In addition, a manual search of the Cochrane Library was conducted and the reference lists of key articles. Key journals (for example, *British Journal of Learning Disabilities* and *Journal of Intellectual Disability Research*) were reviewed for additional published articles.

1.9.3. Search Terms

The researcher was unsure of the number of studies relevant to the topic so conducted a number of searches, starting with a broader search and narrowing search terms to increase funnelling. It was apparent that little literature was available on the topic, therefore, both qualitative and quantitative studies were considered if deemed relevant to the systematic review question.

The search strategy involved three groups of search terms:

- Search terms in relation to the participant group e.g. Learning Disab*; Intellectual Disab*; Developmental Disab*

- Search terms regarding attachment relationships e.g. Attachment*; Relationship*; Bond*

- Search terms in relation to Carers e.g. Care*

Search terms were combined with 'AND'/'OR'/'NOT' Boolean operators and limited to English Language. Appendix I provides a full list of variants considered as part of the search process; many of these yielded no results for the purposes of the systematic review. Appendix II presents a diagrammatic summary of the combination of terms that yielded results for the systematic review, demonstrating the search process undertaken for this purpose. Titles and article abstracts were reviewed (N = 68) in accordance with the inclusion and exclusion criteria, resulting in eight studies for detailed systematic review. Articles and literature generated within the search and identified as relevant to the current study, but which did not meet the inclusion criteria for the focused systematic review, contributed to and are discussed in the wider exploration of literature.

1.9.4. Inclusion and Exclusion Criteria

To be included in this focused review of the literature, papers were required to meet the following criteria:

- Qualitative and Quantitative studies with a focus on the relationships between adults with a learning disability and carers

- Publication within a peer reviewed journal – in an attempt to ensure high quality research was reviewed
- Publication in English

Studies with a sole focus on children with learning disabilities, or family of origin carers were excluded from the review as were review papers of attachment theory having been applied to the learning disability population. Studies where the primary aim was the development of a measure of attachment or the identification of the presence of attachment disorder symptoms rather than the relationship with caregivers were also excluded.

1.9.4.1. The Inclusion of Qualitative and Quantitative Studies

Combining qualitative and quantitative approaches permitted the researcher to access a wider range of literature in order to achieve the aim of the systematic review question. Furthermore, it realises the complementary strengths of both approaches and produces a more comprehensive account of the area under investigation (Bishop & Holmes, 2013). However, tensions exist when including both methods which relates to the different epistemological positions of qualitative and quantitative research. Each approach is typically associated with and judged according to different sets of underlying assumptions and priorities. For example, quantitative approaches are concerned with objective knowledge limited only by technologies of knowing and with a hypothetico-deductive relationship where data confirms or falsifies a theory. Qualitative approaches are concerned with knowledge embedded in value and culture (including the research process itself) and with an inductive relationship where theory emerges from data (Bishop & Holmes, 2013).

Quality criteria will therefore differ for qualitative and quantitative methods because of their different underlying assumptions and aims. The researcher has negotiated the tensions between the different epistemological positions by using different quality frameworks for the studies dependent on their design. The quality of each study is therefore rated against criteria that are meaningful in relation to the epistemological position of the research. It was also important to avoid comparing quality ratings across studies that had used different quality criteria, and studies are considered of good or poor

quality in relation to their methodology relevant quality criteria and only in comparison to other studies rated against the same quality criteria.

1.9.5. Overview of Included Studies

A total of eight studies were included in the systematic review, four qualitative and four quantitative. Table 1.1 provides a summary of the pertinent information identified from each of the chosen papers. This includes the country in which the research was undertaken, the aims of the study, participant demographics, method (recruitment, design, data collection and analysis), results or main themes, conclusions, and an overall quality rating (see Section 1.9.6.). The selected studies demonstrate the range in application of attachment theory to adults with learning disabilities and highlight the potential role of attachment in understanding service users' relationships with carers.

1.9.5.1. *Interactions between Adults with Learning Disabilities and Carers*

The quality of relationships is determined not only by effective communication but also by the mutuality of affect, ideas and activities that are displayed by both partners within a relationship (Damen *et al*., 2011). Recognising cues from service users, appropriate interpretation followed by the choice and execution of an appropriate response, are a combination of interactive skills that has been labelled as 'sensitive responsiveness' (Salter Ainsworth *et al*., 1978). Individual differences in sensitive responsiveness have been shown to predict differences in the quality of attachment relationships between children and professional caregivers (Ahnert *et al.,* 2006; De Schipper *et al*., 2008) and also to children with or without disabilities and their parents (De Wolff & Van IJzendoorn, 1997; Atkinson *et al.,* 1999; Van IJzendoorn *et al.,* 2007).

Antonsson *et al.* (2008) aimed to illuminate carer's reflections on their interactions with adults with learning disabilities. Participants engaged in stimulated recall interviews about previous video recorded interactions between service users and carers. The authors report that carers reflected on both successful and unsuccessful interactions, and the influences and consequences of each. Examples of successful interaction included understanding cues, satisfying needs, and managing challenging behaviours, and the carers reflected that successful interactions influenced the sense of security, confidence and satisfaction of the

service users. Failing to understand cues, failing to satisfy needs and failing to manage challenging behaviour were examples of unsuccessful interactions. The consequences of such failings were reflected by carers to be irritation, aggression and violence among service users.

Carers reported feeling that a good relationship with mutual understanding supported successful interactions. Many of the concepts discussed in relation to good relationships reflect those used to describe attachment relationships, including the need to feel safe and secure, mutuality, respect, shared language, connection and responsiveness. Antonsson *et al.* (2008) outline implications for interventions aimed at strengthening the competence of carers and developing strategies for managing challenging behaviour.

Damen *et al.* (2011) also focused on the interactions between people with learning disabilities and professional caregivers and aimed to improve the quality of interactions through the use of a video-based intervention programme. Supporting sensitive responsiveness is included as an important component of the programme, the effectiveness of which has been demonstrated in a previous study with children and caregivers (Janssen *et al.,* 2003). The authors report that the onset of the intervention coincided with improvements in important aspects of the quality of interaction between service users and carers and that the overall quality of interaction became more characterised by affective mutuality. Damen *et al.* (2011) report that this is indicative of a more harmonious sharing of experiences and emotions and that this characterises attachment security in children and adults. A professional caregiver can, therefore, be considered as a 'secure base figure of convenience' (Waters & Cummings, 2000, p.168) for children and adults with or without learning disabilities. However, physical workload, caregiver burden and service user-to-carer ratio have been demonstrated to have an effect on the quality of interaction in group care for young children without disabilities (de Schipper *et al.,* 2007, 2009) and may, therefore, play a role in group care for persons with disabilities (Damen *et al.,* 2011). Therefore, a realistic goal for services for people with learning disabilities might be the partial assuagement of attachment needs (Clegg & Lansdall-Welfare, 1995).

1.9.5.2.   Attachment Theory as a Framework for Understanding and Planning Clinical
Interventions

Clegg and Lansdall-Welfare (1995) drew upon attachment theory as a framework for understanding difficulties experienced by people with learning disabilities and used this to inform three planned clinical interventions. The difficulties described by the authors were formulated to reflect attachment insecurity and included: intermittent and disproportionate expressions of distress or anger; a resistance to exploration of the physical world (e.g. becoming distressed when encouraged to go on day trips or holidays); difficulty in intellectual exploration and completing tasks well below cognitive ability; a significant 'fixation' on a particular professional or family carer; and the expression of anger or distress in selected settings. Other factors identifying individuals for whom attachment theory may serve as a useful explanation took into consideration background and context. This included: an early history of additional life threatening impairments that have the potential to compromise relationship-building; transitions across the lifespan that can trigger problems (e.g. a move from school to day centre); and an individual being in professional care for some time.

The authors describe a sequence of priorities for clinical intervention which included: the provision of support for carers feeling overwhelmed by enmeshed relationships with service users; the building of a secure base for service users through the use of individual psychotherapeutic interventions with an external professional and/ or development of the role of carefully selected staff to provide a secure base for an individual; and supporting the emotional development within the setting over the long term by increasing staff understanding of attachment issues, helping them to clarify boundaries of support to develop and maintain their relationships with service users. The interventions facilitated change in three areas: reduction in anger and distress; increased exploration of physical and intellectual environments; and an increase in the range of people to whom the service user relates (Clegg & Lansdall-Welfare, 1995).

1.9.5.3.   Attachment Styles and Behaviours that Challenge
Clegg and Sheard (2002) investigated the relationship between challenging behaviour and insecure attachment. A survey of staff and carers involved with a cohort of 54 school-

leavers with severe learning disabilities demonstrated that 34% of students were rated by placement staff as 'over-investing' in one or few relationships. This became a source of jealousy, a response which was considered to reflect attachment insecurity. Students without such relationship-specific problems were significantly less likely to show challenging behaviours, while those with difficulties were more likely to be living outside of the family home. The authors highlight the clinical relevance of attachment difficulties, and reported that although treating behavioural issues such as separation protest with behavioural intervention or medication may reduce the intensity of the distress, neither adequately address the root of the problem that is embedded in key relationships. They argue the need for more detailed and longitudinal research into the relationship between attachment status and challenging behaviour.

Larsen *et al.* (2011) aimed to investigate whether adults with mild/moderate learning disabilities could accurately self-report their attachment style, and explored the relationship between attachment style and challenging behaviour and/ or mental health problems. Service user and carer participants completed a questionnaire based on Hazan and Shaver's (1987) attachment categories and mental health diagnoses. Carers also provided information about challenging behaviour. The authors reported findings demonstrating that adults with mild/moderate learning disabilities show the same range of attachment styles as the general population. Links between challenging behaviour and insecure attachment were also found in addition to an association between depression and insecure-avoidant attachment. The study demonstrates that some adults with learning disabilities can accurately report their attachment style based on inter-rater agreement across service user and carer participants. However, the authors raise a key issue about the accuracy of one person judging the attachment style of another when the experience of attachment is a personal and private one, observed in adults via behaviour towards significant others or self-reported (Larson *et al.,* 2011).

1.9.5.4.   Attachment Representations

Differences in the quality of caregiving interactions and emotional responsiveness between service users and carers may also be explained and influenced by the attachment representations of individuals. Internal working models of relationships may influence

interactive behaviour, biasing attention and interpretations of attachment-relevant cues and attachment-related events (Schuengel *et al.,* 2013). Schuengel *et al.* (2012) used the Adult Attachment Interview (AAI; George *et al.,* 1996) to investigate attachment representations of professional caregivers who had participated in an intervention study that aimed to improve interactions between people with learning disabilities and carers (Damen *et al.,* 2011). Twenty-eight out of 51 caregivers were classified within the autonomous attachment category (participants who are able to describe attachment-related experience in a way that is believable when experiences are described as generally positive and reasonable when negative); 12 were classified as dismissing (participants who idealise their attachment-related experiences, based on a lack of supporting concrete memories, and deny the negative impact of difficult experiences); and 11 as preoccupied (participants who display current, involved anger regarding attachment relationships, or appear mentally enmeshed with ill-articulated, vaguely described attachment experience).

As described earlier, Damen *et* al. (2011) report improvement in interaction quality from baseline to intervention, indicated by confirmation of and responsiveness to signals from service users and affective mutuality. Schuengel *et al.* (2012) demonstrate that caregivers with dismissing classifications continued to show less confirmation of service users' signals, and those with dismissing or preoccupied classifications improved their responsiveness to the level of caregivers with autonomous classifications. The authors, therefore, conclude that attachment representations may modify in some ways the impact of interventions to improve caregiving.

1.9.5.5. *Attachment Relationships*

An attachment relationship that exists between two people can be differentiated from other types of relationships by a history of one person directing attachment behaviour to a particular other person who tends to respond to the attachment behaviour. However, no quantitative criteria exist to determine whether two persons are in an attachment relationship or not (Schuengel *et al.,* 2013). Attachment relationships are assumed between child and primary caregiver, and may or may not develop between partners in long-term romantic relationships (Cassidy, 1999). Attachment behaviours demonstrated by adults

with learning disabilities towards professional caregivers (Clegg & Sheard, 2002) suggest that attachment relationships may also be found within residential care.

Relationships between adults with learning disabilities and carers tend to be lengthy and intensive, in addition to a frequent need for practical support for service users. Given that previous research has demonstrated the impact of a positive working alliance on successful treatment outcomes and/ or service users' emotional well-being (Orlinksky *et al.,* 1994, 2004; Duncan *et al.,* 2004), Roeden *et al.* (2011) suggest that it is desirable for a positive working alliance between service users with a learning disability and carers. They used the 'nominal group technique' (NGT) to discover what adults with learning disabilities feel contributes to a successful working relationship with carers. The results revealed that from a service users' perspective the way in which carers deliver support is important and that participants regarded reliability, empathy and a non-patronising attitude adopted by carers as contributing to successful relationships.

In another study, Hermsen *et al.* (2014) investigated professional loving care for people with a mild learning disability from the carers' perspective through the use of semi-structured interviews. The authors were interested in the ability of carers to offer a human degree of care within a context of commercialisation and shrinkage of possibilities to provide professional loving care. Within the field of care ethics, the authors highlight a focus on essential values for the building of relationships, including responsibility, care and involvement. A high quality interpersonal relationship and a professional loving approach are considered necessary conditions for quality care. One of the five main categories identified by participants in the study related to the 'facilitating factors for the provision of professional loving care' (Hermsen *et al.*, 2014). Twenty-one out of 28 carers indicated that the provision of professional loving care was intrinsically connected to an underlying attitude and identity. Essential to this was the building of a relationship of trust that gives service users a feeling of safety and security. This reflects the potential for carers to provide a secure base for adults with learning disabilities. In the study undertaken by Clegg and Sheard (2002) previously discussed, the authors also report that free comments added to their survey contained key identifiers of attachment relationships, including specific relationship jealousies and the importance of proximity for the service users to carers.

1.9.5.6. Summary of Included Studies

Eight studies are included in the systematic review, four qualitative and four quantitative. These studies demonstrate the range in application of attachment theory to adults with learning disabilities and highlight the potential role of attachment in understanding service users' relationships with carers. Attachment theory has informed interactions between adults with learning disabilities and carers; it has been used as a framework for understanding and planning clinical interventions; and the literature has investigated: attachment styles and behaviours that challenge; attachment representations; and attachment relationships. The quality of the studies included will now be discussed.

Table 1.1   Summary of Studies Included in the Systematic Review

Authors; Country	Aims	Participant Demographics	Method (design, data collection, data analysis)	Results/Main Themes	Discussion/ Conclusions	Quality Rating
Antonsson *et al.* (2008); Sweden	To illuminate carers' reflections on their interactions with adult people with learning disabilities.	16 total: 9 female, 7 male. Age range 21 to 62 (Median = 43) Two to 35 years (Median = 17) of experience working with people with learning disabilities. 15/16 had basic nursing education at high school or university level.	Recruitment: Carers recruited via larger project. Design: Qualitative study as part of a larger project. In previous study, interactions between residents and carers recorded on video. Recordings made daily for 1-2 weeks, for 2h at a time. Data Collection: Tape recorded and transcribed Interview Schedule: Stimulated recall interview after watching previously recorded video of interaction with service user Data Analysis: Qualitative content analysis.	Carers reflected on interactions as successful and unsuccessful. Successful Interactions: Understanding cues; satisfying needs; managing challenging behaviour. Unsuccessful Interactions: Failing to understand cues; failing to satisfy needs; failing to manage challenging behaviour	Carers reflected on the influence of successful interactions on security, confidence and satisfaction among the residents; and the consequences of unsuccessful interactions: irritation, aggression and violence among residents. Carers experienced feelings of inadequacy following unsuccessful interactions. Findings related to Buber (1994) ways of relating to another (I-Thou and I-It). If carers have the courage to be near and let residents into their lives, interaction is successful = mutual awareness, respect and reciprocity (I-Thou). When carers and residents perceive each other as consisting of specific, isolated qualities (I-It), it is a relation of distance and detachment. Both ways of engaging are useful. A good relationship supported successful interaction. Humour and joy could be useful in creating mutuality and a good relationship. Implications for educational initiatives and interventions aimed at strengthening carers' competence in their work with people with learning disabilities.	**17/20**
Clegg & Lansdall-Welfare (1995); UK	To describe the use of models of unassuaged attachment behaviour derived from attachment theory as a framework for understanding and planning	3 total: 2 female, 1 male. Age range 26-43. One client with severe LD; two with moderate LD.	Recruitment: Report of interventions via clinical work, therefore, clients described in the report were via referral to the teams. Design: Qualitative based on three case reports. Data Collection: not reported Interview Schedule: not relevant	Themes from the clinical interventions are reported: Identification: current pattern, background and context. Facilitating change: working with ambivalent carers,	All of the interventions yielded significant client change in three areas: reduction in anger and distress, increased exploration of physical and intellectual environments, and an increase in the range of people to whom the client relates. Outcomes related to theoretical aspects including separation and loss, and service implications of staff turnover. Limitations of clinical findings discussed and need for more systematic examination with a	**8/20**

	three clinical interventions.		Data Analysis: not reported	building a secure base, emotional development within the setting.	wider range of individuals. Authors suggest further research – attachment status of people with learning disabilities who are not displaying clinical distress, and prevalence of attachment-related problems.	
Clegg & Sheard (2002); UK	To explore whether secure/ insecure attachment plays a role in challenging behaviour	Staff and carers of 54 school leavers (25 men, 29 women), severe ID, aged between 20 and 26 years (mean = 23 years) 41 lived with parents; two with non-parental family members; three within Adult Placement Schemes; and two in residential care; data unavailable for six individuals.	Recruitment: Database on a cohort of school leavers. Carers of school leavers approached to take part, permission received for 54 individuals. Design: Cross-sectional correlational survey. Data Collection: Completed returns for 43 people were received from both the main carer and a representative of that person's main day placement. Measures: Survey of 24 questions about behaviour in the past three months, one question assessed 'over investment' behaviour (Sheard et al, 2001). Data Analysis: Fisher's Exact Test and two-tailed chi-square tests.	Thirty-four per cent of students were rated by placement staff as 'over-investing in one or a few relationships which become a source of jealousy'. Students without such problems were significantly less likely to show challenging behaviours, while those with them were significantly more likely to be living outside the family home.	Results from analysis of the answer to a single survey question are no more than indicative. The data supports the contention that a proportion of challenging behaviour derives from insecure attachment. Free comments added to this survey contained key identifiers of attachment relationships: relationship jealousies were specific and proximity was important. Clinical relevance: although treating separation protest with behavioural intervention or medication might reduce the intensity of distress; neither addresses the problem which is embedded in key relationships. The preliminary results justify more detailed and longitudinal research into the relationship between attachment and challenging behaviour.	**10/36**
Damen et al. (2011); Netherlands	To test the efficacy of the Contact programme for improving the quality of interaction between	Clients and caregivers of a care organisation. Clients lived with 24hr support in different units.	Recruitment: Clients selected based on 5 criteria. Exclusion criteria reported and rationale for exclusion described. Design: A-B design across subjects (clients and their team of caregivers). Data Collection: Time	From baseline to intervention, significant increases were found for the frequency with which caregivers confirmed signals of clients, for the proportion of	The start of the Contact programme coincided with improved quality of interaction between professional caregivers and clients with visual and learning disabilities in group homes. The significant improvement in affective mutuality indicated that clients and professional caregivers showed more	**19/24**

	professional caregivers and persons with visual and learning disabilities living in group homes.	12 clients with visual and learning disabilities Age: 13-54 years (M = 35yrs). Seven male; five female. Mod LD = 2 Severe LD = 5 Profound LD = 5 Partial sightedness = 5 Blind = 7 72 caregivers completed all phases of study. 13 male; 59 female. Age: 20-58 years (M = 30.0yrs).	sampling coding system - 10min video recordings of observations (5min for video-feedback intervention; 5min for observation coding selected at random). Measures: Quality of interaction – categories and indicators as quantitative measures and qualitative rating scale for affective mutuality (Pianta, 1994). Social Validity Scale – components of interventions rated by caregivers. Data Analysis: Mean score across raters for the four indicators created an indicator of quality of each session. Repeated measures ANOVA, planned comparison, post-hoc tests	initiatives taken by clients that were responded to by the caregivers, and the affective mutuality as a quality of the interaction. No significant increase in client responsiveness observed. Caregivers evaluated the intervention as useful and feasible.	harmonious sharing of experiences and emotions after the start of the video-feedback intervention. Open sharing of emotions with caregivers is characteristic of attachment security in children and adults alike. Professional caregivers can be 'secure base figure of convenience' (Waters & Cummings, 2000, p. 168) for children and adults with learning disabilities. Limitations reported and further research suggested.	
Hermsen et al. (2014); Netherlands	To examine the internal morals of care staff. To identify initial motivation for working as a care professional, the conditions for providing professional loving care, and the effects of commercialisation of care according	28 care staff working at five care organisations. 18 female, 10 male. Age: <20 = 1 20-30 = 4 30-40 = 8 40-50 = 10 >50 = 3 Unknown = 2. Employment	Recruitment: Qualitative sampling strategy, namely accidental sampling. Sample size based upon saturation as well as resources and available time. Design: Qualitative study using semi-structured interviews. Data Collection: audiotaped and transcribed. Interview Schedule: Two pilot interviews held to support development of the Interview	22 core codes and 5 main categories of codes were identified. Inspiration for working in the field of care; Facilitating factors for the provision of professional loving care; Impeding factors for the provision of	Consideration given to the commercialisation of care and shrinkage of the space for the offering of professional loving care from a critical perspective. According to care staff, the building of a relationship of trust with a client and recognition of a client lies at the base of professional loving care. The care relation can only be compassionate when there is contact and trust. Care staff are finding it increasingly difficult to meet the needs of clients and experience a threat to enable offering professional loving care. This is due to	17/20

45

	to care staff. And to explore the required elements for the rearrangement and adjustment of the care situation in the future.	experience from under 5 years to over 30 years (4 unknown). Highest level of education: 13 vocational; 13 university; 2 unknown. Function of care staff: 14 direct care; 3 direct care assistant; 8 direct care ambulant; 3 social therapist.	guide. <u>Data Analysis:</u> Qualitative data analysis and normative ethical reflection. Atlas.ti computer programme used for the purposes for data reduction.	professional loving care; Commercialisation of care; Desires question.	increased precedence given to the smooth running of production processes over investment in direct contact with clients. Concerns about declining motivation and loss of work satisfaction as a result of the commercialisation of care are only partly acknowledged by care staff. Recommendations for more interdisciplinary dialogue regarding the engagement of care staff and moral reflection within care organisations.	
Larson *et al.* (2011); UK	Pilot study to investigate whether adults with mild/ moderate learning disabilities could accurately self-report their attachment style. Explored whether there is a relationship between attachment style and challenging behaviour and/ or mental health problems. Examines	60 adults with learning disabilities (51.7% male) and 39 people who supported them (59% reported knowing the participant with LD for more than two years, all reported knowing the participant with LD at least fairly well and 41% very well).	<u>Recruitment:</u> Participants recruited from organisations providing services for people with LD, including housing associations, charities and colleges. Participants with LD asked to select a supporting person to complete a questionnaire about them. <u>Design:</u> Cross-sectional, correlational survey questionnaire design. <u>Data Collection:</u> Data was gathered using numbered self-report questionnaires with text and selected Makaton symbols to aid understanding. Participants asked to complete questionnaires as	People with mild/ moderate LD show the same range of attachment styles as the general population. Links between challenging behaviour and insecure attachment were found and there was an association between depression and insecure-avoidant attachment.	At least some people with LD can accurately report their attachment style. Attachment patterns in adults with LD may not be as different as has been previously suggested. Validity and reliability of the adapted questionnaire has not been established. There is a need for a more robust measure of adult attachment style that is suitable for use with people with LD. Applications of attachment theory in individual therapy and at a policy level are explored in light of the findings, as well as directions for future research. There appears to be a relationship between insecure attachment and depression in people with LD. This has implications for the psychological treatment of people with LD and interventions should be	15/36

	distribution of attachment styles in people with learning disabilities, based on the hypothesis that it might be different to the general population.		independently as possible. Measures: Questionnaire for participants with LD requested details of age, gender, living situation, relationship status, history of mental health problems and attachment style. Supporting person questionnaire requested details of length of time supporting the person, how well (Likert Scale) they knew the person, any mental health problems diagnosed by a Doctor in the person with LD, any challenging behaviour and three attachment statements. Data Analysis: Pearson's x^2-test.		developed that focus on attachment relationships. Attachment behaviour may not be linked to challenging behaviour as directly as has been previously suggested.	
Roeden _et al._ (2011); Netherlands	To gain insight into the conditions and aspects clients with intellectual disabilities value in their relationship with caregivers.	17 in total (in 3 groups). Gender not specified. Age range: 25-56 years (Mean = 41). All clients lived alone in assisted housing. 15 mild LD; 2 borderline range.	Recruitment: Participants visited by first author and asked if they wanted to participate. Design: Qualitative study using a structured method for collecting data. Data Collection: All initial responses written down during individual interview; then read aloud and recorded on flipchart; then a ranking process is utilised. Measures: The nominal group technique (NGT) used to provide a structured method	Top ten ideas from each group presented. Combined highest scoring ideas also presented. Demonstrates that the attitude and approach by the caregiver (empathic, reliable and non-patronising) are considered important.	NGT valuable in bringing to the fore the opinions and priorities of clients with learning disabilities. Results also related to basic assumptions of Solution focused brief therapy. Results reveal similarities to those derived from research into client-professional working relationships among children and adults in the general population. The opinions expressed could be used as items in standardised questionnaires regarding client-caregiver relationships.	**17/20**

			for collecting and organising thoughts of a group of people with regard to a single question. Modified for use with people with learning disabilities. Data Analysis: The four NGT steps followed by each separate group.	Reliable relationships, in which caregivers adopt an interested attitude, make time and listen well, were viewed as valuable attributes by the research participants.		
Schuengel et al.(2012); Netherlands	Used the Adult Attachment Interview (AAI) to investigate attachment representations of professional caregivers who participated in an intervention to improve interaction with children and adults with visual and learning disabilities (Damen et al., 2011).	51 caregivers, 18% male; 82% female. 65% had a higher vocational education degree. Average age of 31.0yrs. On average 8.6yrs experience in working with people with LD. 12 clients in study same as above Damen et al., (2011) study.	Recruitment: Participants recruited from professional caregivers working in 12 group homes. Design: As in Damen et al., (2011) study. Data Collection: Trained interviewers (not involved in the coding of the recordings) made appointments with the caregivers for conducting the AAI. Transcribed verbatim and scored by the first author, who was blind to the interaction codings. Intervention as in Damen et al., (2011). Measures: AAI (George et al., 1996) used to assess mental representations of attachment – semi-structured interview. Other measures as described in Damen et al., (2011). Data Analysis: as described in Damen et al., (2011).	Of the caregivers, 28 classified as autonomous, 12 as dismissing, and 11 as preoccupied. Unresolved loss or trauma not included in the analyses. Caregivers with dismissing or preoccupied classifications improved their responsiveness to the level of caregivers with autonomous classifications.	Attachment representation may modify in some ways the impact of interventions to improve caregiving. While caregivers with autonomous classifications improved without support during the baseline period, caregivers with preoccupied or dismissing classifications only showed improvement after they had received interaction coaching. Limitations of study described – number of caregivers with unresolved/disorganised reactions to loss/trauma was too small to conduct four-group comparisons or two-group comparisons. No follow-up data available to investigate if whether intervention effects sustained.	20/24

1.9.6. Quality Frameworks

Three quality frameworks were required for the systematic evaluation of the articles, one for the qualitative papers and two for the quantitative studies. In order to weight the clinical significance of findings according to study quality, a numerical scoring system was added to the existing rating guidance for each of the quality frameworks. Each of the criteria on each framework was scored as follows:

Score of '2' =   when the answer to the question was 'Yes' and/or criteria were fulfilled

Score of '1' =   when the answer to the question was 'unclear' and/or criteria were partly fulfilled

Score of '0' =   when the answer to the question was 'No' and there was no evidence of the required criteria, or the criteria are not reported on

Ratings were also discussed with the researcher's research supervisors to enhance the reliability of scores. The total score for the different quality frameworks differs due to the number of criteria assessed on each.

1.9.6.1.   Quality Framework for Qualitative Studies

A qualitative quality framework developed by Cardiff University's Specialist Unit for Review Evidence (SURE) was utilised for the qualitative studies (SURE, 2013). The checklist has been adapted and updated from the former Health Evidence Bulletins Wales (HEBW) checklist with reference to the National Institute for Health and Care Excellence (NICE) Public Health Methods Manual (NICE, 2012a) and previous versions of the Critical Appraisal Skills Programme (CASP) checklists. Because ten areas of quality are assessed the highest possible score for the qualitative studies is 20. Table 1.2 shows the quality framework criteria and scores for each of the four qualitative studies.

1.9.6.2.   Quality Frameworks for Quantitative Studies

Two quality frameworks were selected and adapted for the evaluation of the quantitative studies. One checklist was provided by NICE (2012b) and was used to evaluate the quality of the correlational, cross sectional designs. The other was the Single-Case Experimental Design (SCED) Scale proposed by Tate *et al*. (2008) which was used to evaluate the quality of

the single case designs. Both were selected on the basis of the compatibility between the framework and the studies, but neither framework included information on ethical considerations. Therefore, a question regarding ethical issues was added to each of these frameworks by the researcher. The correlational, cross-sectional checklist assesses 20 areas of quality (including additional ethics criteria) and therefore has a total possible score of 40. However, one criterion was not applicable to the two studies evaluated, so the highest possible score was 38. The SCED assesses 12 areas of quality (including additional ethics criteria) and therefore, a total score out of 24 is given. Tables 1.3a and 1.3b show the quality framework criteria and scores for each of the four quantitative studies.

Table 1.2   Qualitative Framework for Qualitative Studies (SURE, 2013)

Quality Framework Criteria (for qualitative studies)	Qualitative Studies Scoring Guidance: 2 = Yes (criteria were fulfilled); 1 = Unclear (criteria partly fulfilled); 0 – No (no evidence of criteria/not reported)			
	Antonsson *et al.* (2008);	Clegg & Lansdall-Welfare (1995)	Hermsen *et al.* (2014)	Roeden *et al.* (2011)
1. Does the study address a clearly focused question/ hypothesis?	**Yes:** Clear aim, importance and relevance stated. Focused review of literature.	**Yes:** Clear aim of the application of a theoretical framework to three clinical situations described. It's importance is highlighted and comprehensive literature review presented	**Yes:** Clear aims of the study are described following a focused review of the literature.	**Yes:** Clear goals of the study described. Review of relevant literature.
	Score: 2	Score: 2	Score: 2	Score: 2
2. Is the choice of qualitative method appropriate?	**Yes:** The study sought to illuminate carers' reflections on their interactions with adults with learning disabilities.	**Yes:** The paper sought to describe three clinical interventions.	**Yes:** The study sought to understand the carer's perspective.	**Yes:** The study sought to gain insight from clients with learning disabilities and rationale for method used is provided
	Score: 2	Score: 2	Score: 2	Score: 2
3. Is the sampling strategy clearly described and justified?	**Yes:** Participants selected via involvement in a larger study which explains their involvement in the current study. Relevant characteristics are reported. Also reported that no participants chose not to be part of the study or wanted their participation to stop.	**Unclear:** The authors report referral of the clients and request from staff teams for multidisciplinary intervention. Detailed information provided about client characteristics. Not clear why these clients were chosen to be reported on over others.	**Yes:** The authors report a quantitative sampling strategy, namely accidental sampling. Detailed information provided about participant demographics.	**Yes:** Detailed information provided about participant characteristics and how they were approached. Information about total number approached and total number who participated included reason for one participant not taking part and those who did not participate throughout the whole process.
	Score: 2	Score: 1	Score: 2	Score: 2

4. Is the method of data collection well described?	**Yes:** The setting for data collection was described and appropriate. Clear information about data collection and method. Location of interviews reported. Opening question of interview guide stated and content of interviews commented on.	**No:** No information provided about how data was collected or collated to report on the clinical interventions used.	**Yes:** The setting for data collection was described and appropriate. Sufficient information about data collection method. Pilot interviews used to develop semi-structured interview guide and areas/questions of focus reported. The authors report that sample size was based on saturation and resources/time available. They report that to identify saturation, data collection and review were conducted parallel to data analysis.	**Yes:** Detailed description of data collection and adaptations to method for client group. Questions used and procedure reported. Content of materials used also included in report. Details of training of interviewers in the method also described.
	Score: 2	**Score: 0**	**Score: 2**	**Score: 2**
5. Is the relationship between researcher(s) and participants explored?	**No:** No indication of consideration of researcher bias.	**No:** No indication of consideration of researcher bias.	**Yes:** The researchers report on the potential for researcher bias in the analysis and interpretation of data. Reflexivity re: their own standpoints on professional loving care, the commercialisation of care is reported, and attempts to reduce bias.	**Yes:** The authors report that the clients were previously unknown by the first author who made initial contact during recruitment. Details are given about the interviewers, none of whom worked in direct professional support services to guarantee independent positions. Clear guidance also reported about how to respond to participants.
	Score: 0	**Score: 0**	**Score: 2**	**Score: 2**
6. Are ethical issues explicitly discussed?	**Yes:** Ethical approval gained from University. Approval gained from relevant authorities and service managers. Informed consent gained from participants. Consent established between researchers and relatives of residents. Participants informed of voluntary nature of the study and right to leave. Consent included agreement re: use of recordings,	**No:** Details about ethical considerations or standards not given.	**Unclear:** Consent for audiotaping the interviews is reported to have been obtained from participants. No other details are reported about ethical issues.	**Unclear:** Information given to clients is described. Anonymity of data emphasised to participants. Details of permission for research given. Some ethical considerations not clearly reported e.g. ethical approval or informed consent.

	and storage. Consideration given to confidentiality to reporting of data.		
	Score: 2	**Score: 0**	**Score: 1**	**Score: 1**
7. Is the data analysis/ interpretation process described and justified?	**Yes:** Clear analysis procedure reported. Some quotes included in results. Analysis performed by three authors and audited by a fourth.	**No:** No description of an analysis process.	**Yes:** Description of analysis process undertaken and computer programme used. Two independent coders of data, 20% of the interviews found to have 82.62% agreement.	**Yes:** Clear and detailed description of how the concepts were identified in the data. Analysis performed within the three groups.
	Score: 2	**Score: 0**	**Score: 2**	**Score: 2**
8. Are the findings credible?	**Yes:** Explicit reporting of findings under themes. Summary of findings outlined and related to the aim of the research. Findings related to relevant theoretical model of relating. Results are compared to other studies. Relevance for practice is discussed.	**Unclear:** Themes reported on are based on clinical intervention not on data collected.	**Yes:** Explicit reporting of findings reported and quotations used to illustrate themes/codes. Findings are compared to other studies. Implications for clinical practice are discussed.	**Yes:** The findings are based on the original data and explanation for the results is provided. Results are compared to other studies.
	Score: 2	**Score: 1**	**Score: 2**	**Score: 2**
9. Is any sponsorship/ conflict of interest reported?	**Unclear:** Sponsorship reported via acknowledgement to those who provided financial support but unclear if this is a conflict of interest.	**No:** No information included.	**No:** No information included	**No:** No information included.
	Score: 1	**Score: 0**	**Score: 0**	**Score: 0**
10. Did the authors identify any limitations? Are the conclusions the same in the abstract and the full text?	**Yes:** Some methodological limitations discussed. Conclusions are consistent across abstract and full text.	**Yes:** Limitations of outcomes discussed and of methodological implications. Conclusions are consistent across abstract and full text.	**Yes:** The authors identified limitations of the study re: sample size and single geographical area. Conclusions consistent across abstract and full text.	**Yes:** The authors discuss limited scope of the study re: number of participants and select group. Methodological issues for the method used also reported. Conclusions are consistent cross abstract and full text.
	Score: 2	**Score: 2**	**Score: 2**	**Score: 2**
Total quality score (Total = 20)	**17/20**	**8/20**	**17/20**	**17/20**

Table 1.3a   Quality Framework for Quantitative Studies – correlational and cross-sectional designs (adapted from NICE, 2012b)

Quality Framework Criteria (for correlational cross-sectional designs)	Quantitative Studies Scoring Guidance: 2 = Good (criteria were fulfilled); 1 = Unclear (criteria partly fulfilled); 0 – Poor (no evidence of criteria); NR = not reported; NA = not applicable	
	Clegg & Sheard (2002)	**Larson *et al.* (2011)**
1.1 Is the source population or source area well described?	Unclear: Age range, gender, severity of LD and living arrangements of the school leavers are described. Some data unavailable. Little information re: carers who were the informants.	Unclear: Gender, severity of LD and country and area of residence are described. Age and relationship status are reported to have been asked within the survey questionnaire, however, these are not reported.
	Score: 1	Score: 1
1.2 Is the eligible population or area representative of the source population or area?	Cross-sectional survey of a relatively small sample of 43 individuals from a database on a cohort of school leavers. Completed returns for school leavers. Very little information so no evidence of criteria.	Relatively small sample of 60 individuals with mild/ moderate LD who are in contact with a range of service provisions across three regions.
	Score: 0	Score: 1
1.3 Do the selected participants or areas represent the eligible population or area?	Participants were school leavers with severe LD but carers were the informants. Very little information so no evidence of criteria.	Relatively small sample of 60 individuals with mild/ moderate LD not measured directly but authors confident of presence due to funding requirements by local authorities. Authors acknowledge crude method of approximating level of LD.
	Score: 0	Score: 1
2.1 Selection of exposure (and comparison) group. How was selection bias minimised?	Participants recruited via a database on a cohort of school leavers. No reported evidence of minimised selection bias.	Participants recruited from a range of organisations providing services for people with LD. Selection bias not reported.
	Score: 0	Score: 1
2.2 Was the selection of explanatory variables based on a sound theoretical basis?	Yes: Related to previous theoretical background and research literature.	Yes: Related to previous theoretical background and research literature.
	Score: 2	Score: 2
2.3 Was the contamination acceptably low?	NA	NA
	Score: NA	Score: NA
2.4 How well were likely confounding factors identified and controlled?	No confounding factors acknowledged but survey only.	No confounding factors acknowledged but survey only.
	Score: 0	Score: 0

Left side row labels: 1. Population; 2. Method of selection of exposure (or comparison) group

	2.5 Is the setting applicable to the UK?	Likely, details of ethnicity and country of residence not reported. Authors based in UK and funding from UK based commissioning group. Survey questions in English Language.	Likely, details of the services, area and country of residence reported but ethnicity of participants not described. Authors based in UK.
		Score: 1	**Score: 1**
3. Outcomes	**3.1 Were the outcome measures and procedures reliable?**	The authors acknowledged that the use of one question to assess attachment is limited. No validated outcome measures, use of survey only.	The authors acknowledged that validity and reliability of the adapted questionnaire has not been established.
		Score: 0	**Score: 0**
	3.2 Were the outcome measurements complete?	NR	NR
		Score: 0	**Score: 0**
	3.3 Were all the important outcomes assessed?	The survey asked one question to identify attachment style and 24 questions about behaviour. Open comments on the survey also described attachment issues and are reported. No further detail reported.	Designed own questionnaires for study, used self-report measure adapted from attachment categories. Authors acknowledge no tools exist to evaluate attachment style via informant report and self-report measures of attachment have been adapted for use by LD population. Questionnaires asked for details on objective and subjective aspects under investigation in the current study.
		Score: 1	**Score: 1**
	3.4 Was there a similar follow-up time in exposure and comparison groups?	No follow-up reported.	No follow-up reported.
		Score: 0	**Score: 0**
	3.5 Was follow-up time meaningful?	No follow-up reported	No follow-up reported
		Score: 0	**Score: 0**
4. Analyses	**4.1 Was the study sufficiently powered to detect an intervention effect (if one exists)?**	Small sample size, no mention of power analysis	Small sample size, no mention of power analysis
		Score: 0	**Score: 0**
	4.2 Were multiple explanatory variables considered in the analyses?	Comparison of those who did and did not have relationship jealousies, at home or placement, found no effect of gender, communication skill or presence/absence of siblings. No further explanatory variables in the analyses reported.	Effect of questionnaire order on attachment style reported – no significance. Relationship between participant and supporter ratings of attachment and mental health is presented and both sets of results reported.
		Score: 1	**Score: 1**
	4.3 Were the analytical methods appropriate?	Fisher's Exact Test used to assess statistical significance in the analysis of the contingency table. Suitable for small sample size. Two-tailed chi-square tests used to compare those	Owing to the categorical nature of the data, associations between variables such as mental illness, attachment style and challenging behaviour, were examined using Person's x^2-test. The level of

		without problems to those with other problems.	agreement between attachment style reported by LD participant and their supporting person was also calculated using a x^2-test.
		Score: 2	Score: 2
	4.4 Was the precision of association given or calculable? Is association meaningful?	Statistical associations and clinical relevance presented and discussed. Open comments on the survey also presented and discussed. Results acknowledged as indicative.	Statistical associations and clinical relevance presented and discussed.
		Score: 2	Score: 2
5.Summary	**5.1 Are the study results internally valid (i.e. unbiased)?**	Convenience sample, small sample size, potential biases not reported.	Convenience sample, small sample size, potential biases not reported. However, authors acknowledge key issue re: how accurate people are in judging the attachment style of another person, therefore, inter-rater disagreement will always be likely.
		Score: 0	Score: 1
	5.2 Are the findings generalisable to the source population (i.e. externally valid)?	Small sample size, individuals from one database on a cohort.	Small sample size, however, individuals representative across three large regions and from a variety of service provisions for people with mild/moderate LD. Authors acknowledge the pilot status of the study.
		Score: 0	Score: 1
	6. Ethical Considerations: Was ethical approval sought and received?	The authors report permission received for individuals involved in the study. Ethical approval from a relevant body not reported.	The authors report an information sheet for participants and informal assessment of comprehension to ensure understanding of the task and statements. Ethical approval from a relevant body not reported.
		Score: 0	Score: 0
	Total quality score (Maximum Score = 40, however, 2.3 not applicable for both studies, therefore, maximum score = 38)	**10/38**	**15/38**

Table 3.1b   Quality Framework for Quantitative Studies – single-case experimental designs (adapted from Tate *et al.,* 2008)

Quality Framework Criteria (for single case experimental designs)	Quantitative Studies Scoring Guidance: 2 = Yes (criteria were fulfilled); 1 = Can't Tell (criteria partly fulfilled); 0 – No (no evidence of criteria)	
	Damen *et al.,* (2011)	**Schuengel *et al.,* (2012)**
1. Is there sufficient clinical history specified?	Background characteristics of both clients and caregivers provided including: gender, age, severity of LD, visual impairment, communication level, years of employment with clients, number of working hours.	Same as Damen et al., (2011)
	Score: 2	Score: 2
2. Are the target behaviours described? Are precise and repeatable measures used and operationally defined?	Detailed description of target behaviours – quality of interaction (categories and indicators). The variables based on discrete interactive behaviours are explained and the construction of the combination scales used.	Same as Damen et al., (2011) with additional information in relation to the measurement of attachment representations of caregivers using the AAI.
	Score: 2	Score: 2
3. Is the study design either A-B-A <u>or</u> multiple baseline?	A-B design across subjects. Authors report a drawback of the procedure that it was not possible to fully conform to the multiple baseline design.	Same as Damen et al., (2011)
	Score: 1	Score: 1
4. Has an adequate baseline measure been provided? Was sufficient sampling conducted pre-treatment?	Baseline period between 5 and 9 weeks – two observations with each caregiver. Authors report that stability of baseline ratings could not be established during the experiment itself.	Same as Damen et al., (2011)
	Score: 1	Score: 1
5. Was sufficient sampling of behaviour/target behaviour conducted during treatment?	Duration of intervention = 9 weeks, in which three observations were carried out with each caregiver.	Same as Damen et al., (2011)
	Score: 2	Score: 2
6. Data record: Are raw data points reported?	Mean values (and standard deviations) of quality of interaction indicators on baseline and intervention measures grouped by client participant are reported.	Preparatory analyses of data reported.
	Score: 2	Score: 2
7. Observer bias? Is inter-rater reliability established for at least one measure of target behaviour?	Observations rearranged in random order before they were rated, to keep raters naïve to the phase of the intervention, to eliminate the possibility of expectation bias as an explanation of positive change. Inter-observer agreement on the measures reported (80%).	Raters blind for intervention phase and attachment of the caregiver coded the recordings in a randomised order. Trained interviewers (not involved in the coding of the recordings) completed the AAI with caregivers. AAIs scored by the certified first author, who was blind to the interaction codings.

	Score: 2	Score: 2
8. Were independent assessors used to reduce assessment bias?	The authors report use of 12 raters due to length of data collection and large amount of videotapes. Independence of assessors not reported.	AAI assessors independent to AAI coder.
	Score: 1	Score: 2
9. Was statistical analysis used?	Mean score across raters for the four indicators created an indicator of quality of each session. Repeated measures ANOVA, planned comparison, post-hoc tests	Two-way ANOVA with attachment category and client as factors on the dependent measures. Bonferroni-corrected post-hoc tests used.
	Score: 2	Score: 2
10. Was the treatment replicated either across subjects, therapists or settings?	Intervention replicated across subjects and allowed for a test of whether the intervention effect differed among the clients, however, statistical power of this test was not strong (0.44)	Intervention replicated across subjects, however, statistical power not reported in this paper.
	Score: 1	Score: 1
11. Was evidence for generalisation demonstrated?	The authors report potential threat to the validity of the findings – the effect of multiple testing. Small sample of clients, therefore authors advise caution with generalisation beyond clients in the study. However, larger number of professional caregivers, high participation rate and robust effect across clients and teams lend confidence to the expectation that the Contact programme might also be effective for professional caregivers in other group homes.	The authors discuss the study based on single case experimental design not a randomised clinical trial with caregivers and clients randomly assigned to experimental and control groups. Variability due to differences among clients and interaction settings was minimised and the number of caregivers exposed to the intervention was maximised, allowing for a stronger focus on caregiver factors. Authors caution against generalisability to other clients due to small sample size, to caregivers, generalisation can be made with more confidence. Interaction effect highly replicable across clients and group homes.
	Score: 1	Score: 1
12. Ethical Considerations: Was ethical approval sought and received?	Authors report approval from local ethics committee. Criteria for selection reflect ethical considerations e.g. consent from parents or representatives for clients, professional caregivers consent, a desire to improve quality of social interaction, clients in group homes informed of videotaping with positive/ neutral response.	Informed consent for the participation of the clients was obtained from parents or other legal representatives. The study protocol was approved by the care organisation's ethics committee.
	Score: 2	Score: 2
Total quality score (Maximum Score = 24)	**19/24**	**20/24**

1.9.7. Narrative of the Quality Review

The systematic review focused on how attachment theory has contributed to understanding attachment issues in adults with learning disabilities and their relationships with carers. In this section the quality of the studies included will be discussed. Four studies included in this review employed a qualitative design. One study (Clegg & Lansdall-Welfare, 1995) scored eight out of 20 and the other three (Antonsson et al., 2008; Hermsen et al., 2014; Roeden *et al.*, 2011) were all rated 17 out of 20 according to the SURE (2013) criteria. The other four studies included in this review employed a quantitative design for the phenomena under investigation. Two studies utilised a cross-sectional correlational design. Clegg and Sheard (2002) had a quality score of 10 out of 38 and Larson *et al*. (2011), a score of 15 out of 38. The final two papers report different outcomes from the same research study that utilised an A-B multiple baseline design for single case experiments. Damen *et al.* (2011) had a quality score of 19 out of 24 and Schuengel *et al.* (2012), a score of 20 out of 24.

1.9.7.1.   Research Aims, Methodology and Design

All studies provided a clear aim for the research, which was justified in terms of relevance to literature and practice. All studies also selected appropriate methodologies in relation to their aims. For qualitative studies, the area of research design was problematic for Clegg and Lansdall-Welfare (1995) due to no reported description of the analysis undertaken to arrive at the main points they included in the paper. With a quality rating score of eight out of 20 this study is considered of poorer quality and, therefore, its contribution to understanding the attachment issues in adults with learning disabilities and their relationships with carers is more dubious. The other three qualitative studies (Antonsson et al., 2008; Hermsen et al., 2014; Roeden *et al.,* 2011) make a more reliable contribution with ratings of 17 out of 20 being indicative of good quality research.

For the quantitative studies, there are some inherent difficulties associated with the specific designs employed, including methodological limitations of correlational designs and single case experiments. The cross-sectional survey and correlational designs employed by Clegg and Sheard (2002) and Larsen *et al.* (2011) cannot be used to infer causality and the researchers acknowledge the tentative nature of the conclusions drawn. Furthermore,

Clegg and Sheard (2002) highlight their use of a single survey question to assess attachment style as no more than indicative when such assessments typically involve the use of a combination of observation and interview methods. Thus, the extent to which one survey question offers a reliable and valid measure of attachment style is questionable and Clegg and Sheard's (2002) quality rating of 10 out of 38 is indicative of poor quality research. Larson *et al.* (2011) also acknowledge that the validity and reliability of the adapted questionnaire used in their study had not been established. However, the authors highlight that theirs was an initial pilot study conducted to broadly assess the possibility of people with learning disabilities reporting on their attachment style. Their score of 15 out of 38 indicates research of a better quality than Clegg and Sheard (2002), however, it is still of a relatively poor quality. Larson *et al.* (2011) call for the development of tools that enable closer and more detailed examination of attachment issues in relation to attachment style and the applicability of such measures to the broad range of people with learning disabilities.

This review also identified two papers based on one intervention study that utilised an A-B multiple baseline design (across individuals) for single case experiments (Damen *et al.*, 2011; Schuengel *et al.*, 2012). The quality rating scores of 19 out of 24 and 20 out of 24, respectively, are indicative of good quality examples but with some limitations. The chosen design enabled testing the coincidence between the start of interaction coaching and improvement in interactive quality. However, such studies are limited in terms of their ability to generalise their findings to the wider population (Barker *et al.*, 2002) due to their use of a single case design. Variability due to differences among clients and interaction settings was minimised, and the number of carers exposed to the intervention was maximised, this allowed for a stronger focus on caregiver factors. Due to the small number of service users included in the study and a statistical power of 0.44, generalisation to other clients should be made with caution. However, the researchers suggest that generalisability to other professional caregivers can be made with greater confidence. Schuengel *et al.* (2012) also acknowledge that the number of caregivers with unresolved/ disorganised reactions to loss or trauma was too small to conduct four-group or two-group comparisons. Larger sample sizes would be required to investigate whether findings from previous research demonstrating that adolescent mothers with unresolved attachment were

particularly unresponsive to an intervention aimed to improve sensitivity (Moran *et al.*, 2005) are true of professional caregivers.

A further methodological limitation of the intervention study reported is that no follow-up data were available to investigate whether the intervention effects were sustained for caregivers with different attachment representations (Schuengel *et al.*, 2012). Follow-up data may have also been useful to elucidate long-term effects of the intervention programme, for example, whether effects on interactive behaviour of the caregivers and on the quality of interaction would lead to changes in the functioning of clients (Damen *et al.*, 2011).

1.9.7.2.   *Recruitment and Data Collection*

The majority of studies described appropriate recruitment strategies for the aims of the research. Antonsson *et al*. (2008) make reference to their study being part of a larger project from which their participants were accessed and Hermsen *et al.* (2014) describe the use of a quantitative sampling strategy, namely accidental sampling. Some studies commented on potential participants who chose not to take part. For example, Roeden *et al.,* (2011) provided information about the total number approached and the total number who participated, and included explanation about those who were excluded from the study. With regard to quantitative studies, potential selection biases are prevalent across all cross-sectional surveys. For example, Clegg and Sheard (2002) recruited from one cohort of individuals via a database.

Detailed descriptions of data collection were provided for three of the qualitative studies, but this information was not provided by Clegg and Lansdall-Welfare (1995). For the intervention study (Damen *et al.,* 2011; Schuengel *et al.,* 2012), details are provided in relation to the minimisation of expectation bias during data collection. Strategies were used to ensure that raters were blind for the intervention phase and the coding of the recordings was completed in a randomised order. Furthermore, the interviewers who completed the AAI with carers were not involved in the coding of recordings and the scoring of them was carried out by a qualified person who was blind to the interaction codings.

1.9.7.3.   Ethical Issues

Several articles did not report any considerations or implementation of ethical standards (Clegg & Lansdall-Welfare, 1995; Clegg & Sheard, 2002; Larson *et al.,* 2011). Where ethical issues were reported, this was in relation to: approval from the local ethics committee, reflection of ethical considerations within criteria for selection, and the consent process for participation (Damen *et al.*, 2011; Schuengel *et al.*, 2012). Antonsson *et al.* (2008) also reported on confidentiality and informing participants of their right to withdraw from the study. Hermsen et al. (2014) and Roeden *et al.,* (2011) also discuss issues of consent, but they do not provide information in relation to ethical permission being sought and approval granted.

1.9.7.4.   Reflexivity

Researcher reflexivity was an aspect of quality that appeared to be well documented in two of the four qualitative studies. No indication of consideration of researcher bias was provided for either Antonsson *et al.* (2008) or Clegg and Lansdall-Welfare (1995). At the opposite end of the quality rating, Hermsen *et al.* (2014) and Roeden *et al.* (2011) report on the potential for researcher bias in the analysis and interpretation of data, including reflexivity in relation to the authors' own standpoints on the topic under study, attempts to reduce bias, participants being previously unknown to persons making initial contact about the research, and details about interviewers' experiences within services.

1.9.7.5.   Data Analysis

Three of the four qualitative studies provided a clear description of the data analysis procedure and provided examples of quotes/ statements from participants to support their results. Analysis was performed either within groups (Roeden *et al.,* 2011), by three authors and audited by a fourth (Antonsson *et al.*, 2008), or by independent coders with 83% agreement (Hermsen *et al.*, 2014). All quantitative studies provided information with regard to statistical analyses used and included information on preparatory analyses and post-hoc tests. However, neither of the reports of the survey studies included any mention of power analysis.

1.9.7.6.   Findings and Outcome

All studies reported findings in relation to the original aim of the research and related the outcomes of their research to the literature included in their introductions.   Many of the studies also related their findings to policy and service provision, discussing the theoretical and clinical relevance of the studies. Limitations and/or directions for future research were also discussed by the studies.

1.9.8. Synthesis of Findings

Each of the eight studies included in the systematic review provide intriguing examples of how attachment theory has been applied in the existing literature and contribute to understanding attachment issues in adults with learning disabilities and their relationships with their carers. Quality ratings indicate some studies of poor quality and others that are of good quality but still with a number of limitations.   Therefore, a contribution to understanding attachment issues in adults with learning disabilities and their relationships with their carers is made but the contribution may be somewhat unreliable. Synthesis of the findings indicates that some relationships between adults with learning disabilities and their carers may be characterised by attachment dynamics. Whilst all of the studies have considered the relationships between adult service users and professional paid carers to a greater or lesser extent, no studies have looked specifically at the relationships between service users and carers living within the context of Adult Placements. Three participants in Clegg and Sheard's (2002) study are reported to have been living in Adult Placement; however, this was a small minority within a total number of 54. Instead, the service context has tended to be day care or residential support provided by a variety of carers per individual.

Furthermore, of the studies reviewed in this section only two of the eight papers aimed to understand the perspective of adults with learning disabilities and the majority chose to focus on factors associated with caregiving and understanding the carer perspective. Although there is limited research available in relation to the attachment issues of adults with learning disabilities and their relationships with paid carers, qualitative data from the service user perspective is even sparser. Of the studies that do exist, it appears that many focus on carers of adults with severe learning disabilities. Research that has sought to

understand the service user perspective tend to recruit individuals described as having a mild/ moderate or mild/ borderline learning disability as demonstrated in the two such studies included in this review.

PART 4: RATIONALE, AIMS AND OBJECTIVES

1.10. RATIONALE, AIMS AND OBJECTIVES OF THE CURRENT STUDY

1.10.1. Study Rationale

Research in the area of Adult Placements has been limited and most previous studies have focussed on the characteristics of providers of Adult Placements (Gage, 1995; McConkey *et al*., 2005); on the recruitment and retention of such providers (Bernard, 2004; Hanrahan, 2006); or the reasons on why people become providers of such placements (McConkey *et al*., 2005; Joshua, 2012). This current study, therefore, aims to investigate service users' experiences of Adult Placements, to gain a detailed and rich insight into the lived experiences of the service users living within the Adult Placements, exploring relationships within the family context, the perceived benefits and challenges to the placements, and perceptions of choice and inclusion in service provision.

The current study was influenced by Government policy which advocates that the views of service users and carers need to be heard in order that direct clinical practice and service development can be informed and driven by the experiences of those accessing the services. Qualitatively exploring service users' experiences of Adult Placements is an original and relevant focus for research and may well help to inform services of the types and quality of services important to people with learning disabilities that meet their needs. The study is also informed by research and theory which contributes towards enhancing the inclusion of adults with learning disabilities as participants within research.

Furthermore, it appears that there is a current struggle within the economic climate to continue to provide the best quality care and support for people with learning disabilities in the community whilst making significant savings within the National Health and Social

Services budgets. It is reported that Adult Placements provide a more cost-effective alternative to traditional community care provisions such as residential care and supported living (Shared Live Plus, 2013) and the continuation of such schemes is supported by British Governments (DoH, 2005). Therefore, investigating how adults with learning disabilities experience Adult Placements may provide an understanding and perspective that can contribute to and highlight implications for clinical practice and service provision.

Theoretical and empirical work applied to the general population has highlighted the role and significance of attachment relationships throughout the lifespan. Within the field of learning disabilities, some research has examined the attachments of infants, children and adolescents, but less has focused on attachment relationships of adults with learning disabilities. Yet emotional attachments are recognised as a core human need and that these are essential to all people with learning disabilities. A review of the available literature has demonstrated that relationships with carers might take on particular significance for people with learning disabilities and could be conceptualised as attachment relationships for service users. This may be of particular significance in long-term Adult Placements due to the nature of the service provision.

1.10.2. Study Aims and Objectives

This study aims to investigate the experiences of adults with learning disabilities in long term Adult Placements. The research will elicit service user views on their experience, as well as those of the placement carers, ensuring a service user focus to the study. In doing this, the current study aims to address some of the gaps in the existing research on service users' experiences of Adult Placements and to add to the existing literature on attachment relationships for adults with learning disabilities.

The broad aims of the study are to:
1. Explore how service users experience and make sense of their Adult Placements, including how they came to be living there, their choice and inclusion in the decision-making process.

2. Consider the service user perspective in relation to the perceived benefits of Adult Placements for adults with learning disabilities as identified in previous research undertaken by Joshua (2012).

3. Consider information elicited in light of previous research relating to the attachment relationships between service users and support staff (Stimpson, 2009). Areas to consider will include:

   - The extent to which service users identify Adult Placement carers as significant people in their lives and the degree of importance that they assign to their relationships with them

   - The type of emotional support that service users value most in their Adult Placement carers and the extent to which these reflect attachment needs i.e. availability of a *secure base* to promote personal development and psychological well-being in adulthood; and a *safe haven* where individuals might seek proximity in times of distress or threat to physical or psychological well-being

   - Key issues of developing and maintaining relationships with Adult Placement carers

4. Explore service users' experiences from the perspectives of Adult Placement carers by:

   - gaining insight into how carers perceive and understand their relationships with service users, and the extent to which they consider themselves to be attachment figures in their individual relationships with service users

   - investigating those factors that carers consider to be important in developing relationships with service users, and how they go about maintaining positive relationships with service users

   - exploring how carers perceive the limits of their role and relationships with service users

CHAPTER 2 - METHODOLOGY

2.1. CHAPTER OVERVIEW

This chapter begins with a description of the design of this study. An introduction to qualitative methods follows, including a justification of the use of Interpretative Phenomenological Analysis (IPA) as the most appropriate methodology to explore the aims of the research. The background to and philosophy of IPA are briefly outlined and consideration given to issues of quality when conducting IPA research. The ethical considerations for this study are also described and the sample is introduced. The methods of data collection, written materials used, and an account of recruitment procedures are presented, and the chapter closes with an account of the process of data analysis undertaken.

2.2. DESIGN

This study aims to provide an understanding of the lives of adults with learning disabilities who live in Adult Placements. The researcher was interested in understanding service users' lived experience, and the nature and significance of their relationships with their carers and other important people in their lives. Qualitative research methods aim to construct meaning around how individuals understand and make sense of events by drawing upon information about how people experience them (Willig, 2008). In order to gain an in-depth understanding of individuals' experiences, a qualitative design was utilised in this study. Semi-structured interviews were conducted with six service users and six carers and aimed to elicit service user and carer perspectives of Adult Placements and the relationships experienced by service users. Qualitative data was collected and analysed in accordance with IPA methodology. The interpretative process enabled the data to be organised into coherent themes that were intended to capture the personal meaning of individuals' experiences as described in their interviews.

2.3. INTRODUCTION TO QUALITATIVE METHODS

Qualitative methods in research tend to be concerned with meaning and are interested in how people make sense of the world and experience events. Researchers are interested in the quality and texture of experience, as opposed to the identification of cause-effect relationships associated with more traditional, quantitative methods. The objective is to describe and understand events and experiences but not predict them (Willig, 2008). Qualitative approaches are complementary to traditional quantitative methods and can account for the range and depth of human experience (Stiles, 1993). Features of qualitative research that are distinguishable from quantitative methods include: the expression of results in words rather than primarily in numbers; the use of empathy as an observation strategy which draws on participants' speech and behaviour, the researcher's own experience and self-knowledge, and intersubjective meanings shared within a society; the understanding and reporting of events in their context; and the advocating of the empowerment of participants as a central purpose of research (Stiles, 1993).

2.3.1. Rationale for using IPA in this research

Qualitative research methods can be, and are, used by researchers with quite different epistemological positions (Willig, 2008). The epistemological stance will inform the theoretical framework from within which the data will be approached and analysed. Therefore, the researcher is required to make a decision about the most appropriate method of data collection based on the research question and how the answer to the question may be best extracted from the data.

The researcher was interested in how individuals (people with learning disabilities) experience two particular phenomena (Adult Placements and service users' relationships with their carers), and the meaning they attribute to their experiences. A qualitative methodology was therefore considered the most appropriate to employ in order to obtain complex details about participants' thoughts and feelings in relation to Adult Placements. Specifically, IPA seeks to understand an individual's lived experience, with a focus on personal meaning and sense-making in a particular context, for people who share a particular experience. How individuals made sense of their experiences, the meaning and

impact, was deemed most important, as opposed to developing a theoretical-level account of the phenomenon that would have been elicited using a grounded theory approach (Smith *et al.,* 2009). The epistemological assumptions and methodological procedures of IPA were complementary to the researcher's position and aims. It could offer an empowering, person-centred approach to understanding the diverse and complex relationships experienced by people with learning disabilities via detailed, nuanced analysis of their lived experiences. IPA considers the richness across each individual case, including divergence and convergence (Smith *et al.,* 2009). The flexibility of the approach has led to its appropriate application to different populations such as its use with people with learning disabilities (Smith 2004), enabling their involvement in research.

2.4. INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)

2.4.1. Background and Philosophy

IPA is concerned with and committed to the examination of how people make sense of their life experiences (Smith *et al.*, 2009). It accepts the impossibility of gaining direct access to participants' life worlds but aims to explore the experience from the participant's perspective, which also necessarily implicates the researcher's own view of the world and the interaction between participant and researcher (Willig, 2008).

IPA emerged in the mid-1990s as an experiential and qualitative approach centred in psychology, and is argued to be as important as the experimental. It draws on and is informed by concepts and debates from three key areas of knowledge, phenomenology, hermeneutics and idiography (Smith *et al.*, 2009).

2.4.1.1. Phenomenology

A philosophical approach to the study of experience, phenomenology is interested in what the experience of being human is *like*, in terms of what constitutes the lived world. Four leading figures most associated with developments in phenomenological philosophy are Husserl, Heidegger, Merleau-Ponty and Sartre (Smith *et al.,* 2009). The work of Husserl (1931) has informed IPA regarding *reflexivity* and *bracketing* (setting aside the researcher's own preconceptions) when endeavouring to understand another's experience. Central to

Heidegger's (1962/1927) contribution is the concept of *intersubjectivity* (the shared, overlapping and relational nature of engagement with the world) and the view of the person in context. Lived experience is, therefore, always perspectival, temporal, and in relation to something. As a consequence, the interpretation of others' meaning-making is central to phenomenological inquiry (Smith *et al.,* 2009). Merleau-Ponty (1962) emphasised the individual nature of experience, due to a person's embodied position in the world. He argued that we can never entirely share another's experience despite observing and experiencing empathy for another. Sartre (1956/1943) contributed to the view of the person as embedded and immersed in personal and social relationships, and explained experiences as dependent upon the presence or absence of relationships to other people.

2.4.1.2. Hermeneutics

Originating in the interpretation of biblical texts, historical documents and literary works, hermeneutics is the theory of interpretation. In IPA, the researcher takes an active role and a double hermeneutic, or two-stage interpretation process, is at work. The participant attempts to make sense of their lived experience whilst, at the same time, the researcher attempts to make sense of the participant making sense of, and their reflections on, their experience (Smith & Osborn, 2008). A second double hermeneutic is at work when theoretical perspectives are applied to the phenomenon as described in the original experience. The researcher is trying to understand the experience from the participant's perspective, whilst analysing and trying to make sense of it (Smith *et al.,* 2009). The *hermeneutic circle* is an idea that provides a useful way of thinking about the iterative nature of the method in IPA research. It concerns the dynamic relationship between the part and the whole, at a number of levels. In order to understand any part, the whole must be examined, but to understand the whole, the researcher must look to the parts (Smith *et al.,* 2009). The process of the hermeneutic circle deepens understanding.

2.4.1.3. Idiography

Concerned with the particular, idiography is in contrast to 'nomothetic' psychology, which makes claims at a group or population level. In IPA, idiography is achieved through commitment to detail and the depth of analysis. The aim is to understand "how particular experiential phenomena (an event, process or relationship) have been understood from the

perspective of particular people, in a particular context" (Smith *et al.,* 2009, p. 29). This explains the use of small, purposively-selected samples in IPA.

2.4.1.3. Using a more diverse sample in IPA

The idiographic approach focuses on the particular which highlights the importance of a single case study in IPA analysis. However, IPA also adopts analytic procedures for moving from single cases to more general statements across cases but which also allow particular claims for any of the individuals involved (Smith *et al.,* 2009). Whilst acknowledging a potential discrepancy with IPA's concern with the particular and, therefore, research with small homogenous groups, the current study is multi-perspectival and considers both the service user and carer perspective on a phenomenon. Limitations of this may include reduced depth to the analysis and less detailed nuances in the results. However, in the current study, each case was treated as a single case in the first instance through the data analysis process as described in Section 2.9.3. The researcher initially considered the service user and carer data as separate and patterns across each of the two perspectives were established. However, it was also possible to synthesise multiple analyses from across the two perspectives at a superordinate level (see Section 2.9.3.6). Smith *et al.* (2009) suggest that bolder, more adventurous IPA designs exploring phenomenon from multiple perspectives can help to develop a more detailed and multifaceted account of a phenomenon.

2.5. ENSURING QUALITY IN IPA RESEARCH

There have been a number of attempts to identify what is required to ensure quality in qualitative research, with some overlap between the different sets of criteria offered (Willig, 2001). For example, authors highlight that the systematic and clear presentation of analyses, grounded in data, and the paying of attention to reflexive issues are important indicators of good practice (Henwood & Pidgeon, 1992; Elliott *et al.,* 1999). However, authors may differ in their approach to evaluation from the particular stance of their preferred methodological practice. The set of seven criteria developed by Elliott *et al.* (1999) were used as a guide to review the quality and rigour of the current research as the

authors are most associated with the phenomenological-hermeneutic tradition (Willig, 2001).

2.5.1. Owning One's Perspective

The researcher should own their perspective by specifying and describing their theoretical orientations, personal anticipations, values, interests and assumptions. This allows the reader to interpret the researcher's analysis and to consider possible alternative interpretations (Elliott *et al.,* 1999). Reflexivity should be attended to at each step of the research process (Malterud, 2001) as the researcher will be aware of some factors in advance and others will become apparent as the research progresses.

The researcher's personal and professional position in relation to the current study is acknowledged via the position statement that follows. The researcher was mindful that awareness of preconceptions, values and assumptions increased through the research process. A reflective diary was kept throughout to capture developments in perspective. Extracts from the researcher's diary can be found in Appendix III. Reflexivity of the researcher was also promoted via regular supervision, and bracketing interviews were undertaken during data collection and during analysis with another trainee clinical psychologist also engaging in IPA analysis. Bracketing interviews can be used to explore how the researcher's assumptions and experiences may be influencing the construction of knowledge (Rolls & Relf, 2006). The interview helped to identify unconscious processes that had not been identified through self-reflection alone, and also how the researcher's expectations and assumptions had changed through the research process.

2.5.1.2. Researcher's Position Statement

I am a white British 34 year old female. I grew up in South Wales and have lived and worked in a variety of urban and rural locations within this area. Most of the participants in this study lived their entire lives in either urban or rural South Wales with a couple of exceptions who originally came from England. I did not know the participants prior to the study and was not working in the geographical areas at the time the study took place. The bracketing interview revealed my affection for Wales and awareness of sharing a Welsh identity with some participants.

I am currently in my final year of clinical psychology training. Prior to training, the majority of my professional experience was across a variety of caring, supportive and professional roles in Learning Disability services. I worked directly with adults with learning disabilities and also with their carers and staff teams, including families of origin, support workers and a variety of professionals. Previous clinical experience increased my awareness of some the difficulties faced by people with learning disabilities, including limited opportunities to develop and maintain relationships with others. I am aware of being informed by and valuing person-centred approaches and concepts of enablement. Whilst training, I have developed a particular interest in attachment theory which has led me to consider the types of attachment relationships available to people with learning disabilities. Although I had experience of similar roles to some of the carer participants' working roles (other than that of the Adult Placement Carer role), I had not cared for individuals in the same way as the carers supported service user participants in the study, i.e. within my own family in my home. I, therefore, did not have first-hand experience of the relationships being studied between the service user and carer participants.

I am passionate about working with people with learning disabilities and the inclusion of service users with learning disabilities in research. I have previously undertaken research within a clinical setting with people with learning disabilities and I became aware of some strong beliefs that I hold about the importance of the service user perspective to the understanding of a phenomenon. I became interested in Adult Placement Schemes for people with learning disabilities during training as I had not come across them prior to this. I do, however, recall conversations with previous colleagues about possible benefits to service users that we worked with if they had opportunity to live within a stable family environment and had access to loving relationships. Such previous experiences have led me to develop some expectations and assumptions about care provision for people with learning disabilities. The research area was developed in collaboration with my clinical and academic supervisors and the topic reflected my interest in the types of relationships available to people with learning disabilities.

My own family narrative has shaped my beliefs about the concept of family, attachment relationships and the importance of an individual's sense of belonging. I have always been interested in how others conceptualise the notion of 'family'. I grew up with my biological mother, my sister (18 months my senior), and a variety of family pets. As a working single mother, my Mum was fiercely independent but also relied on the support of her own parents during my childhood, which has shaped my beliefs about parents supporting children as a lifelong commitment. It also facilitated close relationships with my maternal grandparents; however, my grandfather died when I was eight and my grandmother when I was 12. My grandmother moved in with us during the final year of her life due to ill health and, again, this further shaped my beliefs about reciprocal roles of caring and support across family members.

Further details of my family history, in particular, the role of fathers, are pertinent in terms of framing my beliefs about the meaning of family and my own attachment relationships. I have experienced being part of a family who are not biologically related to me but to whom I feel a sense of belonging and with whom I have developed relationships that are based on mutual care and affection. However, I am also aware that difficult family circumstances have led to complexities in my relationships with some family members. At the same time, my experiences have facilitated resilience, and strengthened other relationships with important people in my life.

I am aware of personal strong beliefs I hold about decisions made and information being withheld in the best interests of another, particularly within relationships that have inherent power imbalances i.e. the parent-child dyad. The bracketing interview revealed the potential impact of my personal beliefs on the interpretation of service users' experiences of their relationships with carers. Reflection on this identified the potential power imbalance within the service user/carer relationship and the wider societal context of powerlessness for people with learning disabilities. Despite some of the more challenging aspects of my family history, I grew up in a relatively stable environment with the availability of loving relationships. This is in contrast to many of the service user participants' experiences of 'home' prior to their current placements.

I grew up in a family that valued privacy and where work was outside of the family home. I am aware of the value I place on my current home as a sanctuary from working life and was mindful of my reaction to the idea of having someone living within my family home finding it difficult to understand why people would want to do it. However, I am also aware of simultaneous beliefs about the development of relationships and the ability of families to adapt to a new family 'norm'.

I currently live with my partner and our two dogs. My relationships with my dogs are very important to me and I am aware of the value I place on such attachments with animals. Several of the service user participants identified feeling close to family pets, dogs, in particular. The bracketing interview revealed that due to my own experience of non-traditional attachment figures it has likely made me more open to hearing about other people's experiences of them. I was, therefore, aware of a potential bias towards hearing about participants' pets within the family home and in my interpretation of the data to place a significant emphasis on such attachments.

2.5.2. Situating the Sample

The researcher should describe the participants and their life circumstances so that the reader can assess the relevance and applicability of the findings (Elliott *et al.,* 1999). In the current study, a description of the participants can be found in section 2.7.3, although information presented is minimal to protect anonymity due to the small size of the population under study.

2.5.3. Grounding in Examples

Examples of the data should be provided to illustrate the analytic procedures used in the study and the understandings generated from them. This allows the reader to examine the fit between the data and the researcher's interpretations and to consider alternatives (Elliott *et al.* 1999). In the current study, quotes are used to demonstrate each theme described. An extract from a transcript is also available in Appendix IV to illustrate the research process.

2.5.4. Providing Credibility Checks

The researcher is required to check the credibility of their interpretations and themes, using any of several methods to do so, including: checking understandings with participants, checking and reviewing the data and interpretations with other analysts, using a different method of qualitative analysis, or where appropriate, triangulating the data with other sources of data available. In the current study, the researcher employed credibility checks with supervisors at several stages of data analysis. This included: examining the analysis process, discussing themes developed and verifying them in the context of the original data, and checking drafts of the results.

2.5.5. Coherence

Analyses should be presented in a coherent and integrated style whilst preserving nuances in the data (Elliott *et al.*, 1999). The story of the data in the current study is presented in Chapter Three via a table of the themes and participant quotes included in the written narrative.

2.5.6. Accomplishing General versus Specific Research Tasks

Clarity of the research task is required in qualitative methods and limitations of the applicability of findings should be specified. If a general understanding of a phenomenon is intended, an appropriate range of cases is required. If the task is to provide insight into a specific case, systematic and comprehensive study of that case is necessary (Elliott *et al.*, 1999). In the current study, the researcher aimed to examine the experiences of adults with learning disabilities living in Adult Placements and their relationships with their carers, from the service user and carer perspective. To achieve this aim, a range of service user and carer participants were sought and are described in section 2.7.3. Limitations of the approach are considered in chapter four, section 4.5.

2.5.7. Resonating with Readers

Finally, the researcher is required to present the information in such a way that the reader connects with the material and judges it as an accurate representation of the phenomenon under study, or that it clarifies or expands their appreciation or understanding of it (Elliott *et al.*, 1999). Such resonance is reminiscent of the third hermeneutic level in IPA, that is, the

imagined reader trying to make sense of the researcher trying to make sense of the participant (Smith *et al.*, 2009). Resonance of the material presented was checked with supervisors via supervision and review of the write-up.

2.6. ETHICAL CONSIDERATIONS

In consultation with supervisors, the researcher gave consideration as to the most appropriate route for ethical approval. As participants were recruited via Local Authority teams and not through UK Health Departments, ethical approval from the National Research Ethics Service for the National Health Service was not required. More appropriately, ethical approval for the study was gained from Cardiff University School of Psychology Research Ethics Committee, as the Social Care Research Ethics Committee recommend that student research be reviewed by University Research Ethics Committees. Ethical approval was gained prior to the commencement of data collection and a copy of the approval letter can be found in Appendix V.

2.6.1. Capacity to Consent

The team members assisting with the recruitment of participants were made aware of the need for participants to have the capacity to provide informed consent and to participate in the research process and were asked to consider this when identifying potential participants. This was outlined in the inclusion criteria (see section 2.7.1). Capacity to consent to participation in the study was also determined through informal assessment of the potential participant's capacity, in line with the Mental Capacity Act for England and Wales (2005). The researcher has training and clinical experience in assessing informed consent and capacity, and specifically with adults with a learning disability. Had there been complex factors in determining capacity and therefore informed consent, the Clinical Supervisors were to be consulted in the first instance. If the issue of capacity could not be readily resolved, then the potential participant would have been thanked for their time and their participation in the study would have ceased. This was outlined in the exclusion criteria (see section 2.7.2).

2.6.2. Informed Consent

The researcher aimed to ensure that all participants were making an informed decision about participating in the research. Specifically, in relation to informed consent provided by participants with a learning disability (DoH, 2003b), the researcher sought guidance from the evidence base and gave the participants extra time when making a decision, used a variety of ways to communicate, and aimed to establish rapport with participants (Cameron & Murphy, 2006). Consent was also considered as an on-going process and sought at different stages of the research process, including, when first approached by team members during recruitment and prior to the start of the interview. All participants were provided with information sheets and consent forms, adapted where appropriate with inclusive communication, to support their decision making about whether to participate in the study (see Appendices VI-XI). These were informed by Cardiff University's procedures and guidance provided by the School of Social Sciences Ethics Review Committee.

2.6.3. Anonymity and Confidentiality

Each participant was allocated a pseudonym. The list of participants and their identifiable pseudonyms was kept locked in a secure cabinet and only the researcher had access to the information that corresponded to the identities of each participant. The pseudonyms were used on all transcripts to ensure data remained anonymous and confidential, and all names were changed during the transcription process. No identifiable information was included in the transcriptions or the write-up. All data was stored separately to the list in the researcher's place of work and was only accessible by the researcher and clinical/academic supervisors. Audio recordings were destroyed following their transcription.

2.6.4. Participant Well-being

The researcher was mindful that discussion within the interviews may raise some potentially emotive/distressing issues for service users and/or carers. Prior to starting the interviews the researcher checked with all participants that they were feeling okay to take part as arranged. It was made clear in the information sheets that if the participant was upset by any part of the research process, the researcher would stop the process and provide emotional support. The researcher was experienced in working with adults with learning disabilities and carers, and in responding to people who may be upset. During the interview

the researcher remained vigilant for any changes in the participant's mood or the possibility that he or she might benefit from a break.

The researcher also ensured that appropriate avenues of support were available should an interview have needed to be stopped or postponed due to participant distress.   Clinical supervisors were prepared to make themselves available to provide additional support to participants if required, in addition to other relevant team members who had been part of the recruitment process and well-known to the participants.   However, such measures were not required as none of the participants became distressed during the interviews.

The researcher received regular supervision throughout the process of the research to ensure her well-being and engagement in ethical practice.

2.7.   PARTICIPANTS

A purposive sample was collected from the two Adult Placement schemes which are well established providers of Adult Placements.   Participants were chosen from these two services so that insight into the phenomenon of Adult Placements for people with learning disabilities could be explored.   Samples are selected purposively in IPA research to remain consistent with its theoretical orientation, thereby representing a perspective rather than a population (Smith *et al.*, 2009).

Due to the idiographic approach of IPA research, samples tend to be small in size and fairly homogenous.   However, the extent of homogeneity may vary from study to study (Smith *et al.*, 2009).   The homogeneity of this study's sample was bound by the relatively low numbers of service users within this population and the predicted ability of service user participants to reflect on personal experience, a desirable factor in IPA research due to the requirement for 'rich' data (Smith *et al.,* 2009).   It was also necessary to divide the sample so that the phenomenon could be understood from more than one perspective – both service users and carers.

Fourteen potential participants (seven pairs of service user and carer participants) were identified by the Adult Placement schemes, and initially agreed to take part in the study. Twelve individuals (six pairs of service user and carer participants) took part in the study, as one pair was not available for interview at the agreed appointment time. Smith *et al.* (2009) recommend between four and ten interviews for professional doctorates. As a multi-perspectival study, where the exploration of Adult Placements from a service user and carer perspective aimed to develop a more detailed and multifaceted account of the phenomenon, six service user interviews and six carer interviews was considered both manageable and adequate for similarity and difference, convergence and divergence analysis (Smith & Osborn, 2008).

2.7.1. Inclusion Criteria

Service user participants could participate in the study if they:

- Were adults, aged 18 or over with a Learning Disability and registered with one of the two Adult Placement schemes included in the study

- Were currently residing in an Adult Placement on a long term or permanent basis

- Had been living in the Adult Placement for at least six months

- Had a level of cognitive ability and communication skills to enable them to provide informed consent and to participate in the research process i.e. this meant that participants needed to have the verbal skills to be able to participate in a conversation where Inclusive Communication tools (visual images) could also be used to support understanding

Carer participants could participate in the study if they:

- Were aged 18 or over

- Had been providing an Adult Placement to the service user on a long term or permanent basis for at least six months

2.7.2. Exclusion Criteria

Exclusion criteria were outlined for the process of data collection; however, it was not necessary to operate them in the current study.

Potential service user participants would have been excluded if they displayed an inability to provide informed consent due to capacity issues such as a cognitive ability and level of understanding that meant an individual was not able to understand the purpose of the study and what was required for participation. The researcher and the Adult Placement Social Workers/Officers supporting the recruitment process remained vigilant to the potential participant's ability to provide informed consent to participate in the study.

As dual consent for the interview pairs was required, potential participant pairs would have been excluded should one not have consented to the other i.e. where the carer did not consent for the interview with the service user to take place or where the service user did not consent for the interview with the carer to take place.

2.7.3. Description of Participants

Of the twelve participants interviewed, four out of the six service users were male and two were female. Two out of the six carers interviewed were male and four were female. Of the pair combinations, there were two male service user/male carer pairs, two male service user/female carer pairs and two female service user/female carer pairs. No female service user/male carer pairs were interviewed.

Eleven of the twelve participants were White British; one participant was of African American heritage on their father's side. Participants lived in urban and rural areas of South Wales. The average service user participant age was 50.66 years (range 23-76) and the average carer participant age was 56.16 years (range 48-70).   The length of placement ranged from two to 14 years.

Service user participants had experienced a variety of different types of care provision previous to their Adult Placements, including living with their family of origin, foster care, respite, supported living, residential homes and large institutions.   All service user participants had experience of at least two or more different types of service provision.

All carer participants had experience of previous and/or current roles within the care sector as support workers, Social Workers or foster carers. Two out of six carer participants were single carers, all the others were married or in a relationship. All carer participants offered placements to other service users in addition to those interviewed on either a permanent or respite basis. Five of the six carer participants had adult children of their own and of a variety of ages, some still living within the family home and some having moved out and living with their own families. Two out of the six carer participants also had grandchildren from their own children and/or from previous foster children.

The pseudonyms given to the participants during the transcription process have been removed for the write-up of the study. Service user and carer participants are instead referred to as 'Service user 1', 'Carer 1', 'Service User 2', 'Carer 2', and so on. This is to ensure anonymity and to facilitate the reader's understanding of the interview pairs. All family members and professionals who were identified during the interview were given a pseudonym to ensure confidentiality and anonymity and these remain as such.

2.8.   WRITTEN MATERIALS

The researcher was mindful that the communication needs might vary within the service user participant group and across the service user and carer groups of participants. The researcher needed to remain flexible to this and accessible versions of written materials for service user participants were developed. The researcher also aimed to reflect individual need in the style and delivery of interviews. Therefore, two schedules were also developed, one for each group of participants, with supporting images that could be used alongside the service user interview schedule to supplement questions. The service user information sheet, consent forms and supporting images for the interview schedule were developed using CHANGE (n.d) and internet resources from an information design service called 'easy on the I' (Leeds & York Partnership NHS Foundation Trust, 2015) recommended by Speech and Language Therapist colleagues.

2.8.1. Participant Information Sheets

A service user participant information sheet (see Appendix VI) and a carer participant information sheet (see Appendix VII) were developed and initially shared with potential participants via the Adult Placement Social Workers/Officers. The service user information sheet included pictures and symbols to augment the written text. The information sheets provided participants with information about the aims and procedures of the study. They outlined why they had been approached to participate and what to expect from participation, including how plans would be made to meet and estimated duration of the interview. They explained the voluntary nature of participation, the right to withdraw from the study and it was made clear that participation would not affect support received. They also highlighted: confidentiality if risk was disclosed; the potential benefits and disadvantages of participation; options in relation to any adverse effects of participation; plans for the results of the research; the research sponsor; and information in relation to reporting concerns or complaints.

2.8.2. Consent Forms

Service user consent forms (see Appendices VIII & IX) and carer consent forms (see Appendices X & XI) were also developed for participants. The service user consent forms included pictures and symbols to augment the written text. Two consent forms were developed for both service users and carers. This was to ensure that consent was sought from both parties for participating in their own interview and for the interview with the relevant other. This was deemed important due to the nature of the topic being studied, as it was likely to yield information regarding the personal lives of the individuals and families involved.

2.8.3. Semi-Structured Interview Schedules

In IPA, the aim of the qualitative research interview is to facilitate an interaction where a conversation occurs which is implicitly informed by the research question (Smith *et al.,* 2009). The researcher aims to grant the participant the opportunity to tell their own stories, to speak freely and reflectively, to develop their ideas, thoughts and feelings, and to express their concerns at some length (Smith *et al.,* 2009). Semi-structured, one-to-one interviews have been the preferred method for collecting qualitative experiential data (Reid *et al.,*

2005). A semi-structured interview schedule is a way of preparing for the likely content of a qualitative interview; it allows the researcher to set a loose agenda, to consider the wording of questions (open and expansive rather than leading and closed), and enables anticipation of sensitive issues (Smith *et al.,* 2009).

Qualitative methods have previously received criticism in relation to their suitability for people who have limited language skills or cognitive impairment due to the demand for reflective and articulate interviewees (Smith, 2004). However, IPA has been conducted with a wider variety of groups, including people with learning disabilities or dementia and those who have experienced traumatic brain injury (Lloyd *et al.*, 2009). Smith (2004) calls for adaptations to guidelines for conducting semi-structured interviews with groups who are likely to struggle in terms of their verbal and cognitive skills. This may include the researcher taking a stronger role than usual in guiding the interview and professional experience with clients to be drawn upon when modifying protocols for collecting data.

The service user and carer semi-structured interview schedules were developed based on the review of the literature on Adult Placements and the relationships that service users with a learning disability experience, and sought to reflect the aims of the study. They were also informed by: the researcher's own curiosity; consultation with research supervisors; two pilot interviews with service users with learning disabilities; and through collaboration with service users and carers. The researcher attended a Teaching and Research Advisory Committee (TRAC) meeting (University of South Wales) which is chaired by service users with a learning disability and included service users, carers and University staff members. Members of the committee included adults with learning disabilities and carers who had experience of carrying out research with other adults with learning disabilities. The researcher sought feedback on the relevance and meaningfulness of the phenomenon under investigation, the research design and the types of questions to be asked. An accessible information sheet (see Appendix XII) outlining the initial research idea was shared to support communication.

Following the pilot interviews and discussions with supervisors, the researcher was alerted to difficulties that service user participants may experience with the abstract content of the

phenomena being studied and limitations in their abilities to express and articulate their lived experience. Previous research undertaken with people with learning disabilities have utilised different exercises to support individuals' contribution to the research process (Stimpson, 2009; Moore, 2013). In the current study, a relationship circle exercise (see Stimpson, 2009) was utilised in the first part of the service user interview to help the participant identify important people in their lives and how close they felt to them. It also acted as an ice-breaker to put the service user at ease and increase their readiness to engage (Smith, 2004). In addition, it gave service users the opportunity to write or draw, enabling communication at a more accessible and concrete level. Open-ended questions with directive prompts were prepared for the second part of the interview to elicit service user thoughts, feelings and experiences. The relationship circle exercise could be referred back to where necessary. The service user interview schedule is presented in Appendix XIII and examples of the images used in Appendix XIV.

The carer interview schedule was more consistent with the recommendations of Smith and Osborn (2008). It comprised of broad open-ended questions supported by optional prompts. The carer interview schedule is presented in Appendix XV.

2.8.4. Debriefing Forms

Following the interviews the participants were taken through the de-briefing form (see Appendices XVI & XVII) which thanked them for their participation and outlined: what would happen with the data they had provided; who to contact if there were delayed adverse consequences; information in relation to confidentiality; and an invitation to receive a summary of the study findings.

2.9. PROCEDURE

2.9.1. Recruitment

The researcher established links with the two Adult Placement schemes via clinical supervisors within areas where the services were based. Initial contact was made with either Social Workers and or the Development Manager based in the teams. The study was explained in detail and assistance requested in identifying potential participants. The

Development Manager informed Adult Placement Officers about the study. Both teams consist of paid Local Authority staff who are very experienced within their field of working with people with learning disabilities and their carers. Gatekeeper letters were received acknowledging the services' support of the research (see Appendices XVIII & XIX). Adult Placement Social Workers/Officers were asked to identify potential participants who would be able to provide informed consent to participate in the research process and amply reflect on their experiences. These team members were then asked to go through the information sheet with potential participants and obtain initial consent. Service users and carers were given the opportunity to ask questions about the study and to clarify any aspects of the research process. The researcher was only be able to contact those who gave consent to take part.

If, following discussion of the study, the service user and carer agreed to take part in the interviews, they were asked to sign the consent forms for participation in the study. The team members then returned the signed consent forms, including participant contact information, to the researcher. The researcher was then able to contact the participants to arrange an interview date and time at a location of the participant's choice. All participants chose a home visit which was undertaken in accordance with Cardiff and Vale University Health Board lone worker policy. A risk assessment was also undertaken for this activity (See Appendix XX).

2.9.2. Interviews

On meeting the potential participants, the researcher went through the information sheets with them (See Appendices VI & VII). Participants were given the opportunity to ask any questions and address any concerns about taking part in the study. The researcher informally assessed the service user participants' suitability for taking part and their understanding of their involvement in the study. If they made it clear that they understood the involvement and implications of participation, they were taken through the consent forms to sign (see Appendices VIII & IX). Consent was also reaffirmed with carer participants. The service user interviews took place prior to the carer's interview. Each interview was recorded using a digital recorder before transcription and analysis. Service

user interviews varied in length from 30 to 80 minutes and carer interviews varied in length from 40 to 90 minutes.

2.9.2.1. Service User Interview

All service user participants were offered the opportunity to have someone else present during the interview, but, all chose to undertake the interviews independent of direct support during the interview. In the first part of the interview, the researcher gained background information and had available the prepared relationship circle exercise (as incorporated within the Service User Interview Schedule – see Appendix XIII). This was designed to provide a broader relationship context and to ascertain who the service user felt close to. Participants were asked to draw a circle/picture of themselves and to think about all the important people in their lives whom they felt close to. They were then asked to position each person around their circle (or their written name if this was preferred) according to how close they felt to them. Those to whom they felt closest, would be closest to their own circle.

In the second part of the interview, the completed relationship circle, semi-structured interview schedule and supporting images (See Appendices XIII and XIV) were used to facilitate conversation about the participant's experience of their placement and their relationships with identified individuals. Clinical experience of working with people with learning disabilities has raised the researcher's awareness of the need to remain flexible and person-centred in relation to individuals' preferred communication methods. Therefore, the researcher tailored the interviews according to the particular communication skills and preferences of the individual. For example, some participants chose to use pictures alongside questions but others preferred only verbal conversation.

2.9.3. Data Analysis

The data analysis procedure for this study was grounded within the heuristic framework for IPA as described by Smith *et al.* (2009) as a set of common processes and principles that can be applied flexibly, according to the analytic task (Reid *et al.,* 2005). Starting with the "particular" and "descriptive", and moving towards the "shared" and "interpretive" (Smith *et al.,* 2009, p. 79), the researcher commits to understanding the lived experience of the

participant and how they make meaning of this experience in their particular context (Smith *et al.,* 2009). Due to the double hermeneutic inherent in IPA, analysis is subjective and results are tentative. However, at the same time the subjectivity aims to be dialogical, systematic and rigorous in its application and interpretations can be assessed by the reader (Smith *et al.,* 2009). The six steps of the analytic process undertaken by the researcher are outlined below.

2.9.3.1. Step 1: Reading and Re-reading

Following transcription of all of the interviews, the first step of IPA analysis was for the researcher to immerse herself in the data, by reading and re-reading the transcripts. This is to ensure that the participant is the focus of analysis. During this step, the researcher noted powerful recollections from the interviews and what she found most striking about the transcripts, in an attempt to bracket off and contain her own ideas and connections, allowing her to "remain with the data" (Smith *et al.,* 2009, p. 82).

2.9.3.2. Step 2: Initial Noting

The second step began with the researcher maintaining an open mind and noting anything of interest within the transcripts. Initial notes and ideas were written in the right-hand margin of the transcripts and enabled the researcher to become familiar with the transcript and to identify how the participant describes, thinks about and understands an issue. The researcher aimed to produce a comprehensive set of notes on the data, from which a "descriptive core of comments" (Smith *et al.,* 2009, p. 83) could develop. The descriptive core maintains a phenomenological focus and stays close to the explicit meaning made by the participant about what matters to them, e.g. relationships, processes, places, events, values and principles, and how they experience such things. Sitting alongside this, more interpretative notes helped the researcher to understand how and why the participant has these concerns. Looking at their language used, considering their context/lived world, and identification of more abstract concepts supported the process of making sense of the participant's patterns of meaning (Smith *et al.,* 2009).

The researcher used three types of notation during this step as suggested by Smith *et al.* (2009), including descriptive, linguistic and conceptual comments. Descriptive comments

highlighted key objects, events or experiences. Linguistic comments focused on the type of language used by the participant and how pronoun use, pauses, laughter, repetition, tone, fluency and metaphor within the transcript could reflect how content and meaning were presented. Conceptual comments moved the analysis from explicit dialogue and towards an overarching understanding of the participant's experience. This stage also drew on the researcher's own experience and theoretical knowledge, between the researcher's pre-understandings and newly emerging understandings of the participant's world. Personal reflection on the researcher's own perceptions and understandings supported the exploration of meaning for participants and reflexive engagement became an important factor throughout the analysis. However, the researcher intended for interpretation to remain inspired by the participant's words and that reflexivity was used to help make sense of the participant's experience (Smith *et al.,* 2009).

2.9.3.3. Step 3: Developing Emergent Themes

At this stage, the researcher had a familiar model of the interview and went back through the transcript and initial notes recording emergent themes in the left-hand margin. This reduced the volume of detail and mapped interrelationships, connections and patterns. As well as recalling the learning obtained via the whole process of initial noting, focus on discrete sections of transcript disrupted the narrative flow of the interview. The participant's experiences were fragmented due to data re-organisation. At this stage, the original whole of the interview becomes a set of parts, which then come together as a new whole at the end of analysis, within the write-up. This is the process described as a manifestation of the hermeneutic circle (Smith *et al.,* 2009). This stage took the researcher further away from the participant and involved more of the interpretative angle of the phenomenon being explored. The resulting themes were derived from both the participant's explicit meaning and from the researcher's interpretations. An example of an extract from one transcript demonstrating steps 1-3 of the data analysis can be found in Appendix IV.

2.9.3.4. Step 4: Searching for Connections across Emergent Themes

This stage of the analysis involved charting how the themes fitted together and allowed a structure that pointed to the most interesting and important aspects. Some emergent

themes were discarded due to the scope of the research. Analysis undertaken on subsequent transcripts required the researcher to revisit earlier transcripts to re-evaluate the significance of some themes. The researcher used methods proposed by Smith *et al.* (2009) to look for patterns and connections between emergent themes:

i) *Abstraction* – putting emergent themes that are similar together and giving a new name for the cluster i.e. super-ordinate themes.

ii) *Subsumption* – the bringing together of emergent themes by a particular emergent theme itself.

iii) *Polarization* – the bringing together of emergent themes due to difference instead of similarity. The oppositional relationship offered a way to organise some of the data.

iv) *Contextualisation* – connections that emerge through the identification of contextual elements and relate to significant key life events or specific narrative moments that are dispersed throughout the transcript e.g. temporal, cultural and narrative themes.

v) *Numeration* – taking into account the number of times an emergent theme presents itself and how this might be indicative of the importance of that theme

vi) *Function* – looking at the specific function of an emergent theme for the participant within the transcript.

Smith *et al.* (2009) emphasise that there is no prescriptive strategy for this process but advises the researcher to note the method by which this step was undertaken. With the aims of the research in mind, the researcher listed the emergent themes and either discarded or grouped them using the methods described above. By oscillating between the whole text and particular parts, the researcher engaged with the hermeneutic circle process to create broad clusters or 'subordinate' themes and gave them a label. The researcher devised a summary table for each participant within which the information could be organised. Relevant quotes and line locations were also recorded in the table to evidence and illustrate each theme. Appendix XXI provides an example of a summary table for one participant demonstrating clustered emergent themes, subordinate themes, and supporting quotes. Following this stage of analysis, the researcher met with her clinical supervisors to discuss and check credibility of the identified subordinate themes in the context of the

original transcripts. The outcome of this was the reorganising of some emergent themes and renaming of some subordinate themes to better reflect the experiences and concepts in within the data.

2.9.3.5. Step 5: Moving to the Next Case

The process so far was repeated for the transcripts for each participant within the sample. In keeping with the idiographic commitment of IPA, each case was treated in its own terms, which required bracketing of the ideas emerging from previous cases whilst working on the next, so far as was possible. This process resulted in the production of 12 summary tables.

2.9.3.6. Step 6: Looking for Patterns across Cases

The next stage of analysis meant looking for patterns across cases and integrating the themes. The researcher initially treated the service user and carer data separately and patterns across each of the two perspectives were established. Two lists of recurrent superordinate themes were compiled reflecting unique idiosyncratic accounts and the participants' shared experience. This resulted in the integration of some themes and the renaming of others. Themes were checked against the transcripts to ensure that they remained grounded in the data. During this process, patterns were apparent across the two perspectives and following consultation with supervisors, the researcher combined the service user and carer superordinate themes resulting in further integration, renaming of some themes and checking against transcripts. One master list of recurrent superordinate themes was produced reflecting the shared experience of service user and carers. However, one superordinate theme that captured a shared experience of the carers only was considered pertinent to the research aims and objectives and is, therefore, also included in the results.

CHAPTER 3 – RESULTS

3.1. CHAPTER OVERVIEW

This chapter presents an overview of the themes that emerged from the IPA analysis of the data collected from the 12 participants. Three superordinate themes, each with several subordinate themes, emerged out of the data analysis across both service user and carer participants. An additional superordinate theme, with four subordinate themes, emerged from the carer interview analyses only. This is included in the reporting of the results as the themes are considered by the researcher to be pertinent to the service user experience of Adult Placements and are related to broader systemic issues that have a potential impact on service users' relationships with their carers. Service user and carer perspectives are presented together to provide the richest possible descriptions of the themes.

Prior to presenting the themes, the content of the relationship circles exercises are summarised. This is to demonstrate how the service user interviews were structured and to provide some contextual understanding of the different relationships available to and experienced by service users. However, it has been necessary to minimise the information presented to protect anonymity due to the small size of the population under study.

3.2. SUMMARY OF RELATIONSHIP CIRCLES EXERCISE

An anonymised example of a relationship circle exercise for one service user participant was typed up and is attached for the reader's reference in Appendix XXII. All participants engaged well with the exercise and appeared to understand what was required of them.

3.2.1. Identifying Important People

Service user participants identified between five and 12 significant others (either individuals e.g. 'Adult Placement carer', or groups of others e.g. 'respite carers' or 'church friends') who were important to them and who they wanted to include in the exercise. The circles on the exercises were therefore representative of an individual person, two or more individuals grouped together, or a group of significant others.

Three participants included members of their family of origin in the exercise in addition to their Adult Placement carers. One service user chose not to include family of origin in the exercise but discussed them in the narrative and another's family of origin were absent from the exercise but brought into the narrative. One service user's family of origin were absent from both.

All participants included members of the wider Adult Placement family in their exercises. This included family members of the Adult Placement carers (children and grandchildren either co-residing or living elsewhere) and/or other service users either having previously lived in or currently also living permanently within the Adult Placement. Three participants also included other paid workers including day service staff and Social Workers. All participants identified peers of importance to them outside of the Adult Placement, for example, friends at day service, college, work, or from other personal relationships. All participants lived with family pets (dogs), two service users identified them as significant others who they felt close to and wanted to include in the exercise.

3.2.2. Levels of Closeness

The participants positioned the circles at differing levels of proximity to their own circle to illustrate how close they felt to the important people depicted in the circles. All participants identified either one person they felt closest to or more than one person who they felt a similar degree of closeness to. All participants named their Adult Placement carers first, as important people who they felt close to (either the carer interviewed or both the carer interviewed and a second Adult Placement carer e.g. carer's spouse). Therefore the Adult Placement carer's circle was positioned either closest to the participant's own circle or at the same distance as the other closest people identified. During their interviews, all participants talked about the other people identified as important and close to them in addition to the carer interviewed.

One participant was able to differentiate closeness between Adult Placement family and friends outside of the Adult Placement but struggled to differentiate levels of closeness between Adult Placement family members. The carers interviewed were those identified via recruitment with support from the Adult Placement teams as the service users' main
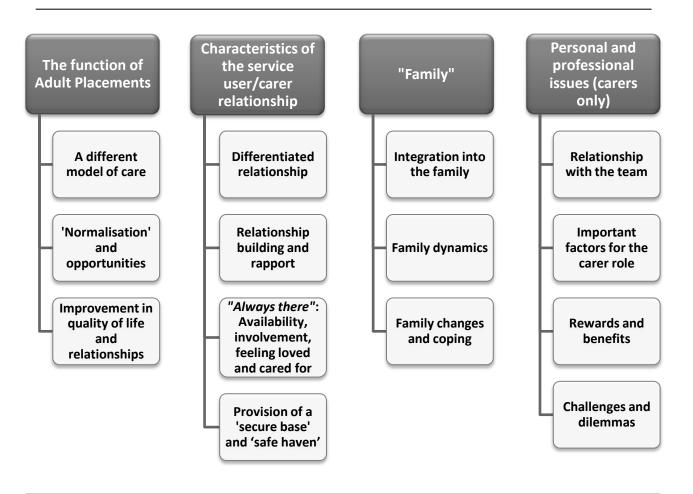
carers. All carers interviewed confirmed they were the person the service user spent most time with and to whom they felt they were the closest.

Participants who included family of origin in the exercise chose to place them further away from their own circles than the Adult Placement carer(s), indicating that they felt closer to the Adult Placement carer(s) than to members of their family of origin.

3.3.   OVERVIEW OF THEMES

An overview of the four superordinate themes derived from the data analysis and their subordinate themes is presented in Figure 3.1. The superordinate themes are in grey and subordinate themes in white.

Figure 3.1: Diagrammatic Representation of the Superordinate and Subordinate Themes

The function of Adult Placements	Characteristics of the service user/carer relationship	"Family"	Personal and professional issues (carers only)
A different model of care	Differentiated relationship	Integration into the family	Relationship with the team
'Normalisation' and opportunities	Relationship building and rapport	Family dynamics	Important factors for the carer role
Improvement in quality of life and relationships	*"Always there"*: Availability, involvement, feeling loved and cared for	Family changes and coping	Rewards and benefits
	Provision of a 'secure base' and 'safe haven'		Challenges and dilemmas

Each superordinate and subordinate theme is described and illustrated with representative quotes from the interviews. Similarities, differences and the range of perspectives within each theme are highlighted as the data is presented and are demonstrated by the quotes selected. Words that have been added to enhance understanding of the data or to remove identifiable elements such as names and locations are inserted in brackets, for example: [text]. Words and phrases that have been omitted from quotes to improve the readability of the text are indicated by an ellipsis: (…). For some participants, sections of the transcripts are used instead of single participant quotes. The data is presented in this format because in some instances the content of what participants said may have limited meaning without the context of the preceding or following questions and discussion.

3.4. SUPERORDINATE THEME 1: THE FUNCTION OF ADULT PLACEMENTS

All service user participants spoke in detail about aspects of the Adult Placements they had experienced which highlighted the uniqueness of the service model and what it meant to them in terms of their lived experience of the care provision. This is described as **THE FUNCTION OF ADULT PLACEMENTS** for service users. **A different model of care**, the concept of **'Normalisation' and Opportunities**, and **Improvement in quality of life and relationships** were integral to their experiences and the meaning associated to Adult Placements by individuals. The latter two subordinate themes (the concept of **'Normalisation' and Opportunities**, and **Improvement in quality of life and relationships**) serve both as integral parts of **THE FUNCTION OF ADULT PLACEMENTS,** and contribute to how Adult Placements may be considered as **a different model of care**. The service user experience was also supported by the carers' perspectives.

3.4.1. A Different Model of Care

The notion that Adult Placements provide something different for people with learning disabilities than other models of care was evident in the accounts of both service user and carer participants. Service User 5 demonstrated their understanding of Adult Placement as **a different model of care**, but their struggle to know what it is was also described:

> *"They are like my family, not, well, like foster family, like, well not adopted either, but like, adult, like, I can't think what to call it"*

This was also echoed in Carer 4's account:

> *"(…) I started working [in a day centre] and somebody had mentioned about the family placement, and like an 'out-brief' of how it worked then, that, similar to fostering, but not (…) 'cause they're adult, in a different format then."*

Carer 6 also expressed a sense of knowing that Adult Placement is different but struggled to explain its difference:

> *"(…) Adult Placement is a complete different ball game, right, to being a foster parent. But it's not that much different, really, you know! (…) but the role – what you do – is very much the same, but with more knowledge, more understanding - because they're grown – they've grown up, and we've evolved, and I do understand their needs, of each individual that we care for, so - it's different; it's hard to explain (…) But I don't look at it as supported living, in any way, shape or form. It's not like that at all."*

All service user participants differentiated their experiences of Adult Placements by making comparisons to previous experiences of support they had received. Service users had experienced at least one other type of service, including: institutionalised care, foster care, care received from family of origin, accommodation for the homeless, supported living and residential care. All participants gave either a general description of difficult previous experiences or a specific example from at least one of these alternative models of care.

Service User 4 described some of what they found difficult when they previously lived in institutionalised care:

> *"(…) sometimes they quarrel there see, and they locks them up then (…) They were very strict there. If you don't behave yourself they lock you up (…) they   make   you scrub the floor in [name of institution] I was doing that once. Scrubbing floors in [name of institution], locked me in a room, you know."*

Service User 5 also gave a description of a previous restrictive experience but within a different provision of care to Service User 4:

"(…) Because if you're stuck in a bedroom for 24 hours you ain't gonna meet anybody, it's not healthy is it? I think my Mum wanted me though locked, well not locked up but didn't want me going out anywhere (…)"

And when asked how their Adult Placement was different to previous care, Service User 6 described a specific difficult experience:

"Well, my old foster Mam, chuck all my clothes out, I went home, I went to see my family then, I went home, back to my foster family house and all my clothes were outside and thrown at me."

From the service user perspectives, the more tangible aspects of care were used to differentiate Adult Placement as a model of care. For Service User 2, the choice, variety and sufficient amount of food available to them at their Adult Placement was very important to them. Having *"plenty of food"* was one tangible aspect of their care that they talked about when asked how their Adult Placement was different to previous care. Service User 1 also used concrete descriptions of service models to demonstrate difference. They made the comparison of mealtimes in an institution vs. a family home:

"When I was in [name of institution] there were 200 boys sat at a big table, yes. Here it's just the one table, just us. It's different. You had to line up for your food in [name of institution] (…) Had to wash up then, we had three sinks, one for washing, one for rinsing, one for drying/dripping the water off the china. We have a dishwasher here (laughs). We would take it in turn in [name of institution], different sizes of plates cos of the different boys, and different cups. Here it's the same, more like family here."

The temporary nature of other service models was also a differentiating factor for some participants when compared to the permanency of Adult Placements. For example, Service User 1 talked about *having* to leave the place they had lived in since a baby:

"(…) When they reached 15 to 16 they had to leave. I left when I was 16. When it came to 16 you had to leave."

97

Carer accounts further supported Adult Placements as **a different model of care** by also making comparisons to previous care received by service users. Carer 1 described previous neglect experienced by Service User 1 when supported elsewhere:

> *"(…) And with [Service User 1], he wasn't very clean, do you know what I mean, he was quite neglected in the home [previous care] (…) left to get on with it, they probably thought he was okay, I don't really know but (…) he wasn't very clean (…)"*

She also gave some specific examples of practical aspects of Service User 1's care needs that have now been met within their Adult Placement:

> *"(…) he didn't wear pants because he was always having accidents (…) he's got false teeth, (…) they were so big and horrible, so he didn't wear them, he didn't wear his teeth. So there sort of things that we've sorted out since he's been with us really."*

Carer 5 differentiated Adult Placement care as *"a more close way"* of working in comparison to support worker care. A sense of freedom and flexibility associated with Adult Placement was present in the narratives of the carers. Similarly to service users' previous restrictive experiences of services, carers shared this experience, albeit from a different position:

> *"(…) when you're a support worker you just come in for a shift; you do what you've been told to do, and it's quite sort of restrictive, and then you just report and you go home, and then another person comes in. Whereas here, it's different (…) it's completely open (…) if we want to pop to the cinema, we just go to the cinema; we don't have to ask management if we can take them out, and what time, and whether another shift's coming on, or any of that; we can just go!"*

The flexibility associated with an Adult Placement as described by Carer 5 was also noted by Carer 4:

> *"I think, if something like this wasn't here, how much they would be missed - you know? Because I know, even in residential homes now, if staff aren't there, nobody can go out, so it's still flexibility."*

Carer 2 used the continuity of relationships to make a different comparison, but one which also differentiates Adult Placements from other models of care:

"I've worked in small group homes; but the turnover of staff in small group homes is immense, and you don't get the continuity; and the residents that live in these small group homes build up a relationship with certain members of staff, only for them to leave; whereas here, it isn't like that. It's completely different; it's a different set-up altogether."

Carer 3 differentiated between models of care by making a connection between what did not work for Service User 3 in supported living and what does work in Adult Placement. This included taking into consideration needs associated with vulnerability and the concept of an Adult Placement providing an individual with a family:

"(...) I think he did actually try supported living for a short period of time, and it didn't work because he lost all his money (…) he would just give it to whoever asked for it (…) so he was quickly put back in the system again (…) but I think he needs the family unit (…) I think he's come on leaps and bounds, being in a family, I really do."

3.4.3. 'Normalisation' and Opportunities

Another essential **FUNCTION OF ADULT PLACEMENTS** derived from the participants' experiences is the concept of **'Normalisation' and Opportunities** available to service users at their Adult Placements. This subordinate theme also relates to the notion of Adult Placement as **a different model of care.** Many of the opportunities described by participants demonstrate the uniqueness of Adult Placements in the sharing of ordinary homes and activities that may not be available to individuals who are being supported elsewhere. One of the carer participants, Carer 5, described this as *"seeing how a normal family is, and how a normal family functions"*.

The service users' shared experience of the patterns of life and conditions of everyday living in Adult Placement appeared as close as possible to the regular circumstances and ways of life or society for non-learning disabled people. All participants described opportunities associated with O'Brien's five service accomplishments including: community presence; community participation; respect, choice and competence (O'Brien & Tyne, 1981). Service user participants tended to describe the opportunities available to them in concrete terms, including, access to work, college, leisure and social activities. This makes reference to

some of the positively valued roles undertaken in society such as consumer, employee, friend and neighbour. When Service User 5 described having the opportunity to engage in ordinary activities, they compared this to their previous situation where such opportunities were more limited:

> *"(…) I wanted my own - not space - but my own independence, going places, you know (…) well before I lived here I was living with Mum.   I used to go out but not far, but since I lived here I do go out. I go to college three days a week, on the bus myself (…)"*

The concept of being able to go out on a bus to college independently is a relatively simple one; however, people with learning disabilities are often denied such opportunities (DoH, 2001a). Having access to everyday, regular activities was a powerful message within the narratives. Furthermore, the autonomy of their own community presence was also noted when Service User 5 said:

> *"(…) well, if I want to go out I go out, or I can stay in (…)"*

There was a shared belief for carer participants that service users would have missed out on opportunities if they had not been supported within Adult Placements.   All carer participants described a variety of daily activities that service users engaged in either independently or with some support. Carers also placed great value on service users' positive roles within the community. One example of this is Carer 1's description of Service User 1's involvement with two local churches that was independent from the Adult Placement family:

> *"(…) then the other thing is he loves his church. From day one we have always made sure he's been able to go (…) he's got two lots of friends (…) He has two lots of harvest festivals and Christmas dinners and they all love him, they absolutely love him (…) it really involves him in the community."*

Carer 6 made reference to the opportunity for service users to be involved in research such as the current project and emphasised the importance of such inclusion:

> *"She's been given lots of opportunities to express herself as well; this, what you are doing is one example (…) it's so important - but it's allowing her to grow, isn't it?*

Allowing her to develop, to the best she can be, you know? There are times when I think [Service User 6] has plateaued, and then she surprises me."

Participants described the opportunity for choice, including: choices available to them within the placement, and their involvement in choosing where they wanted to live. However, service users portrayed different levels of autonomy and control in relation to their move to Adult Placement. Service User 5 explained their decision about where they wanted to live as follows:

"(…) first I was gonna come here on a respite, to try it, but then I wanted to like live here (…) I came with Alys and Carol, who's a Social Worker, both of them brought me here for me to visit. And then I was supposed to come for respite but then I decided I just wanted to live here so I moved in."

Service User 3 also described their involvement in the decision-making process:

"(…) I did have a choice (…) My Social Worker chose here, but I told her as well, I fancied moving somewhere closer to here. I'm happy I choosed here."

Service User 4's experience was different. They described a lack of choice and less involvement in the decision-making process:

"Oh it was a couple of years ago now, the Social Worker said, 'I'll find you a place', she said. So I went to [name of care home] then, for a couple of weeks, and then I come here (…) she [Social Worker] said 'you're moving now see'."

However, all service users described visiting the placement first and meeting the carers and family prior to moving in, as Service User 2 explained:

"(…) up in the other place, they said 'do you wanna go and see [Carer 2] and Paul?', when I was told then, I said, 'I want to go back to [Carer 2] and Paul'. I had all day and then I had to go back home the next day (…) but I said 'I want to go back to [Carer 2]'s'."

The opportunities for independence and competence were also deemed to be an important aspect of the Adult Placement experience. In addition to playing rugby on weekends,

Service User 3 described their competence in activities of daily living; they expressed how they felt about being able to do these things, and had a sense of pride about their responsibilities:

> *"I normally clean the car (…) and I clean the garden (…) Put my clothes away, tidy my room (…) I love it, I do (…) She [carer] tells me, painting now is my job, and gardening. Every Christmas decoration will need to go back up the attic, that's my job. I got them all down this year. I know where everything goes."*

And Service User 1 talked about their opportunity to engage in a valued role on a service user committee:

> *"(…) I used to be on the committee. What you call, the forum (…) We used to have meetings on what was, what we were going to do in the day centre."*

3.4.4. Improvement in Quality of Life and Relationships

The impact of **'Normalisation' and opportunities** on the lives of the service users can be understood in terms of **improvement in quality of life and relationships** which is the third subordinate theme to **THE FUNCTION OF ADULT PLACEMENTS** derived from the data analysis. All service user participants had a shared experience of Adult Placement as having a positive impact on their lives in relation to their general well-being and happiness. This was most neatly summed up by Service User 5 who said:

> *"The best thing? It's changed my life around - When I lived with my Mum, I wasn't so happy, now I live with [Carer 5], I'm more happier than I've ever been."*

 Service User 5 also described what they like about Adult Placement:

> *"I like the different atmosphere (…) It's different living with me Mum, to living with [Carer 5] and [Carer's spouse] (…) I find it better here, I'm not being nasty, but I just find it, the surroundings better."*

However, they also acknowledged that the improvement has taken time when they thought back to how they felt when they first moved in. Confidence played a very important part in the change for Service User 5 and they use a concrete example to describe this:

R: *I was a bit quiet and shy with the family as well, when I first come here, look, in their cupboards, I used to ask all the time (…) but now I just go in there and do it. But when I first moved in I was a bit shy about going in their cupboards. I used to ask all the time, [Carer 5] will tell you that, I used to ask constant, but now I don't now.*

K: What is different now?

R: *I think it's my confidence.*

Carer 6 also described a change in confidence as a benefit of Adult Placement for another service user, in addition to feeling loved:

"The benefits; I think she feels loved, and she's confident - and confidence has grown"

A sense of freedom also featured as an important aspect to the experience of Adult Placement as having had an impact on the **improvement of quality of life**. This was expressed by Service User 1 in comparison to their previous care and they attributed the improvement to having a family:

"It was strict with the [previous caregivers]. More freedom here. More family (…) I have everything I want. I can go for a walk, catch a bus."

When asked what it is like living in an Adult Placement, Service User 2 also described a sense of freedom but in more concrete terms:

"Good (…) Do anything what you want. And then, got my own key and I go to [name of area] and then sometimes I go to [name of area]."

Quality of life was also associated with having more tangible items, as Service User 6 explained:

"My first Christmas I was living here, and my Dad and my Mam [Adult Placement carers], my Mam bought me a TV, I think it was, or no, a CD, it was. And my Dad bought me Sky, oh no, I can't remember the name, but it was my first big present off them."

For Service User 6, the giving of presents was an important aspect to how she perceived her improved quality of life. This was also interpreted by the researcher as representative of her feeling like she belonged in this family which overlaps with the subordinate theme of **integration into the family**. The giving of presents was one way that service users and carers could talk about how they showed the less tangible concept of mutual love and affection.

Improvements in quality of life were also related to skill development and Carer 3 described some observable differences for Service User 3:

> *"(…) he's missed out on bits throughout his life, and suddenly he's a man, and everybody presumes; 'oh, there's this man's body – he can do all this' and he still needs prompting with hygiene (…) He has come a heck of a long way, and lots of people have noticed that, and have said that. But it's just taking the time to re-train him; not presuming "he's an adult and he can do all this", 'cause he can't."*

Service User 6 declared *"I love it"* when asked about Adult Placement and attributed this to being part of *"a big, nice people, nice family"*. Service User 3 described Adult Placement as having been *"fantastic"* for them; they also attributed this to *"having a family"* and whilst acknowledging that they had a family before, they said they had *"no care before"*. The service user participants all shared the experience of having increased access to relationships with others, including: Adult Placement family members, family pets, peers, work colleagues and friendships. One example, described by Carer 3, highlights how Service User 3's relationship with the family pet dog has impacted on his ability to communicate with her:

> *"And he talks a lot through the dog – a lot. Whatever he wants to say, he will say that the dog has said it. He's got a very good relationship with Poppy (…)I think it's someone he can love and trust, you know (…) She's loyal to him; she sits by him; she gets excited when he comes home, and that has been a really big thing to [Service User 3] (…) but there's been lots of things he's said through the dog. "Oh, she said this, she said that"... and I think "Hmmm, right... that's interesting"."*

This example highlights the importance of the relationships that many of the service users had developed with family pet dogs which could be considered as non-traditional attachment relationships. For Service User 3, the dog was a means of communication in addition to an object of love and affection to which the service user could provide care by taking responsibility for walks and feeds. A further example of the importance of such relationships was noted when Service User 1 named the family pet dog immediately after naming the Adult Placement carers in response to a question about who lives at the placement. This was, however, followed by what appeared to be the service user laughing at themselves for identifying the dog. This raised the question of whether there is some discomfort in the recognition of the importance of dogs to some where others might judge such relationships as less important. The service user's laughter was interpreted by the researcher as an acknowledgement of such a potential judgement.

Another example of the **improvement in quality of life and relationships** is one participant's experience of a romantic relationship as described by the carer:

> *"She's engaged to a lad that we have, Will (…) She's got a loving, it's a committed relationship, and we're happy with that; they really care about each other (…) she's no different to any other young woman; she wants to stay with her boyfriend, that's fine with us (…) you know, they have their tiffs – they're no different to you or myself (…)"*

Some participants also experienced an improvement in their relationships with their family of origin following the move to Adult Placement. For example, Adult Placement has offered Service User 5 an opportunity for their relationship with her Mum to develop and improve as might be more aligned to the family life-cycle:

> *"We used to argue all the time, innit, sad mind like that innit (…) we don't argue so much now (…) she didn't want me to come here, she wanted me to go back to her and I said no 'cause I wanted to stay here. In the end now she's okay with the idea now, she's used to it. At least I see her once a month now."*

Carer 2 also described how Service User 2 has had the opportunity to reconnect with a previous neighbour, from which a friendship has developed:

"(…) he's been able to make contact with neighbours that they had (…) and they think the world of [Service User 2] – and they hadn't seen him for two years, and all of a sudden [Service User 2] just turned up there one day – I don't know if it was providence or what – but they're actually a lovely couple; they've taken him down to their caravan (…) And Saturday they're free, he'll go up to see them and then he'll come back for tea."

The **improvements in quality of life and relationships** experienced by the participants were ones that often appear to meet the most basic of needs that may be taken for granted by others but which the service user participants did not always have access to prior to their Adult Placement. Carer 3 reflected on this in their interview:

"I'd love to educate people, in how they don't realise how having a family, and support, can be so important. Just the basics in life are so important. So important! A warm house, you know... [Service User 3] thinks it's wonderful 'cause the house is always warm, and you just think "Goodness me!" (…) And he'll smell [his clean laundry]... when he takes his pile up, he likes the smell of it; and he says it every time. Every time. "I love the smell... I love the smell!" It must be really nice, to him."

3.5. SUPERORDINATE THEME 2: CHARACTERISTICS OF THE SERVICE USER/CARER RELATIONSHIP

All participants reflected on their relationship with the relevant other and as such the second superordinate theme derived from the data analysis was the **CHARACTERISTERICS OF THE SERVICE USER/CARER RELATIONSHIP**.   One of these characteristics was the **differentiated relationship** status to other relationships in the service users' lives. Other defining features included: **relationship building and rapport**; **"always there": availability, involvement**, **feeling loved and cared for**; and **the provision of a 'secure base' and 'safe haven'**.

3.5.1. Differentiated Relationship

All participants identified feeling close to the Adult Placement carers interviewed. This was demonstrated by engagement in the relationship circles exercise and supported by the

narratives. For example, when completing the exercise Service User 4 was able to identify the following:

I: Who would you put closest to you?

B: *Well, [Adult Placement carer], yeah.*

I: OK, so you feel closest to [Adult Placement carer]?

B: *Yeah.*

Some participants also identified feeling close to other family members at the Adult Placement but the main carer was the closest to them, as Service User 3 reported:

I: Who do you feel closest to?"

J: *All of them I'd say [Adult Placement family]. But maybe [carer].*

Service User 5 showed their awareness of their relationship with their carer as different and closer than other relationships, however, they struggled to understand why this might be:

"You see, me and Joanne [friend], are sort of good friends. But it's hard to explain how, like, from a good friend to a carer, now I don't know what the difference is (…) I've bonded more with [Carer 5] than I have Joanne, my friend. Normally, it would be the other way round, innit. You bond more with your friends than you would a carer, but I can't grasp it, how I've bonded more with [Carer 5]."

Carer participants also identified themselves as the person who was most likely to be closest to the service user they support. Carer 6 described Service User 6 as *"my shadow"* and felt they were closer to them *"even above Will"*, Service User 6's fiancé. However, carer participants differentiated the relationship in a variety of ways, including parent/child and landlord/tenant dynamics. For example, Carer 1 demonstrated how she likened the closeness with Service User 1 to a mother/child dynamic and highlighted her attunement to him in comparison to her husband not being as close to Service User 1:

"Mal [carer's husband] has always worked (…) so [Service User 1] was my baby if you know what I mean (…) even now I sort of look at [Service User 1] and I know something isn't right and I might say to Mal casually "something's up with [Service User 1]" and he's like "no, he's alright, he's fine". I guess it's probably like me being a mother, a mother knows the kids best don't they? (laughs)."

Another factor that demonstrated the service user/carer relationship as a **differentiated relationship** from others were examples of proximity seeking behaviour towards carers described by the majority of both service user and carer participants. Such behaviour is considered a defining feature of attachment (Bowlby, 1953) and was portrayed by the response of the service users to the separation from carers. The majority of participants expressed the fact that that they missed their carers when staying at respite. When Service User 3 was asked what it is like being at respite and not at their Adult Placement they said that it is:

> *"Terrible, I miss them (…) I'd prefer to be at home (…) I miss my bed, [Carer 3], and my dog."*

Some participants demonstrated proximity-seeking via their preference for Adult Placement over respite, as Carer 5 described:

> *"If the girls [service users] are given a choice, they would rather stay here (…) they know that we need a break, so they understand it, and they know I get tired (…) They'd rather be here, but they're quite good."*

One service user did not access respite at all and their resistance to it was described by the carer participant. When asked if the service user attends respite they responded:

> *"No – she wouldn't go! You've got to be joking (laughing) no, no. We have a really good understanding. "Don't want to go there!" (..) "I don't need that, Mum" she'll say to me; "I don't need that"."*

Service User 4's experience was different to the others. As previously demonstrated, they had identified their carer as the person they felt closest to, but they described having different interests to their carer and, therefore, they spent less time together in comparison to the other participants. They also stated that they did not miss their carer when not with them. However, different to the other participants, instead of going away to respite, Service User 4 would have the opportunity to stay at home and be supported by the wider Adult Placement family network. Carer 4 also explained:

"I don't think he's got chance [to miss his carer] (…) because my sister's got an iPad, and I take my iPad - I talk to - I face-time him, so he can see me (…) and we'll be chatting, so - and he hasn't missed me that long, because contact is kept"

So proximity is maintained through other forms of contact. This was also demonstrated by Service User 5:

"(…) and then I text [Carer 5] to say I'm on my way home (…) she likes to know I'm safe see (…) If I don't ring or text she'd be worried innit (…) So when I come home from college I always text to say I'm on my way home, 'cause otherwise if I don't do it I know I'd worry too."

3.5.2. Relationship Building and Rapport

All participants identified both a process of **building the relationship** with the relevant other and the importance of **rapport** within the relationship. Both service users and carers described positive experiences of each other and highlighted how well they got on together. However, there was a range of experiences for how the relationships had developed. For example, Service User 2 expressed the idea that the:

"First time I come in here, they liked me and I liked them (…) we hit the ground running (…) we get on really good (…) I have a laugh with [Carer 2] and [second carer]. It's good, I like it."

Others talked about the newness of the situation, as Service User 1 described:

"I was a new person. It was new (…) it was a new adventure".

The majority of both service user and carer participants shared in the experience of it being difficult initially when the service user first moved into the family home. There were examples of participants' awareness of their own trepidation at the commencement of the relationship but also being considerate of the relevant other's position. This was evident from both the service user and carer perspective. Service User 5 described how they felt about meeting their carer as well as considering how their carer might have had similar feelings:

109

> *"(…) I was a bit nervous, like, and I think she might have been a bit nervous meeting me, what I were like"*

Carer 3 reflected on how hard it was from their perspective:

> *"[It was] quite difficult, initially (…) I took the day off... and the old carer came with the rest of the stuff (…) and they were very negative (…) and I kind of panicked; I thought "what have I done?!" (…) "*

And also how hard they thought it was from Service User 3's perspective:

> *Oh, I think it must have been really hard [for him], yes. Suddenly he's turned up at this "other house" again, that he's done since he was very little (…) Probably harder for him than it was for us."*

Compatibility was also identified by carer participants as an integral factor associated with the initial building of the relationship and ongoing connection. Carer 2 highlighted the importance of a matching process that aims for a goodness of fit for service user and carer:

> *"Well, I just feel that he just fitted in; as soon as he arrived here (…) there's a 'matching' process that goes on (…) everyone that comes here has been matched to fit what we can offer here (…) and that is very, very important. Very important."*

Carer 6 acknowledged that there were some behavioural challenges at the beginning that needed to be worked through. However, she also described an immediate connection with Service User 6:

> *"There was sort of no getting to know her, because she was here, and it was instant, and (…) the taking to her was straight away"*

Other participants felt that it took time to get to know each other and that their attachments or relationship bonds took time to develop. For example, Carer 1 described a slower process of relationship building, *"gradually getting to know [the] complete stranger coming to you".* They described feeling *"attached to [Service User 1]"* but that this *"quietly crept up alongside"* their focus on the practical aspects of the service user's care.

3.5.3. *"Always there"*: Availability, Involvement, Feeling Loved and Cared For

Another **CHARACTERISTIC OF THE SERVICE USER/CARER RELATIONSHIP** that emerged from the shared experienced of the participants was the **availability and involvement** of the carer and the sense of participants **feeling loved and cared for** by the relevant other. Knowing that the carer was *"always there"* was really important to Service User 2, as it was to all service user participants:

> *"(…) he's good as gold he is. He'd do anything for you (…) They always do things for me. They're **always there** to help me."*

Availability and involvement was also demonstrated through a rich variety of descriptions from participants about doing things together. Service user participants appeared to greatly value such experiences and spoke about them with excitement and joy, as Service User 6 reports:

> *"Me and Mam go out for a girls day out. Like, we went to Cardiff this weekend to go see um Cinderella. It was me and Mum, Susan and my friend Ruth as well, four of us."*

Although Service User 4 and their carer did not do as much together, they also identified that their carer was always available when they returned home:

> B: *He's always here when I come back.*
>
> I: When you come back from the centre?
>
> B: *Yeah, yeah.*
>
> I: And is that important to you, that he is here when you get home?
>
> B: *Yeah, yeah.*

Carer participants also described enjoying shared experiences, as Carer 3 explained:

> *We do lots of things together; we do gardening together; we clean the rabbits out together; I wash, he wipes the dishes; we go shopping, holidays, out for food; visiting people (…) All parts of family life."*

Participants described a range of experiences of **feeling loved and cared for**. This was either explicitly stated or interpreted through the descriptions of nurture and support from or to others.

Service User 3 explained that they think about their carer as their Mum, but how they imagine a Mum to be rather than one based on their own experience prior to their placement:

> *"I call her Mum in my head, not all the time (…) She's different to my Mum, she's better than my Mother (…) She loves me and cares about me."*

The use of the word 'Mum' here portrays a powerful sense of what it means to be a Mum or a person in a position of providing the love and care that another individual seeks and needs i.e. being an attachment figure to another individual. Service user 3 allows the researcher to make a differentiation between the use of a label of 'Mother' and the embodied experience of being a Mum.

Service User 2 also explicitly stated that *"they care about me"* when asked what they liked about their Adult Placement carers, whereas Service User 6 described feeling cared for in more concrete terms:

> *"She spoils me. And she um, sometimes, she takes me to have my hair cut and have colours, we go to the hairdressers. And I get my nails done, at the nail shop."*

All service user participants described many examples of the support given and received that meant they felt **loved and cared for**, including: aspects of care associated with physical health, practical and financial support. Of significance to the relationships was how such examples of support were implemented. Carers demonstrated their love and care for service users through their understanding of individual needs and their ability to consider things from the service user perspective. As Carer 3 described:

> *"He's a very gentle boy – he's just misunderstood (…) you've got to take it on board that this boy doesn't know right from wrong (…) he just doesn't understand."*

Carer 4 described how necessary it is to know the other person well:

"(…) he won't tell you that he's ill, so you've got to see how [Service User 4] is through how is he walking, or how is - his way of his expression on his face, or his body language"

Carer 6 talked of a balance between caring for and encouraging growth:

"I'm very careful with [Service User 6] (…) her look belies her vulnerability (…) but saying she's vulnerable doesn't mean I haven't encouraged her, don't think I've wrapped her up in cotton wool, because I haven't."

Feeling loved and cared for was not experienced solely by the service user participants. The majority of participants described examples of reciprocated care and support within the service user/carer relationship. Service User 5 expressed the fact that they and Carer 5 would have *"moments"* in relation to times when they would have disagreements. However, they considered that this was most likely at times when Carer 5 was feeling tired. Service User 5 also showed consideration to their carers through their understanding that there may be times when as a married couple, their carers needed time together and on their own:

"Sometimes I sit in the room with [Carer 5] and [carer's spouse], and watch telly with them, 'cause they got a fire in there and they like to light the fire, you know, or sometimes, if they want a bit of time to theirselves I can go to my room and watch telly, you know."

Carer 1 described examples of where they have felt cared for by Service User 1:

"I don't know if I'm misreading that, but he'd do anything for me, he does. And when Carol [fellow service user] used to have goes at me, that used to really upset him."

And Carer 3 described mutual care and support following a difficult time for the family:

"I mean he doesn't understand it, but he's been like a rock to me (…) I was lucky to have him then, if you like (…) So we help each other (…) and I would have been very lonely without him."

Carer 6 described her relationship with Service User 6 as a mother/daughter relationship and talked about feelings of love being reciprocated by Service User 6:

> *"(…) she's very much like my daughter, and we're very much like mother and daughter, in a way that I haven't shared myself with everyone that's passed through my doors, you know (…) But I think it's because she's so giving, and she's so loving, and she's so openly affectionate."*

3.5.4. Provision of a 'Secure Base' and 'Safe Haven'

Another essential **CHARACTERISTIC OF THE SERVICE USER/CARER RELATIONSHIPS** derived from the participants' experiences is the **provision of a 'secure base' and 'safe haven'** for service users. This was described by participants as the type of emotional support valued most within the relationship. It also reflects the attachment needs of the individuals i.e. the availability of a **'secure base'** to promote service user development and psychological well-being in adulthood; and a **'safe haven'** which individuals could turn to at times of distress.

3.5.4.1. The provision of a 'secure base'

Stability, predictability, safety and security provided by Adult Placement carers and from which service users' growth, development and exploration could occur were described in the interviews. Service user participants reflected on how they felt in comparison to previous experiences. For example, Service User 3 said:

> *"I been through a lot. Really hard my past (…) I feel safe here."*

Similar to other service user participants, Service User 3 had lived in an unpredictable environment previously and with an unpredictable caregiver, as described by Carer 3:

> *"And something he did for a long time (…) is he would creep down the stairs in the morning (…) and he'd look right in my face, and he'd say "Morning?" … questioning (…)apparently (…) he never knew what mood his Mum would be in (…) he was sussing out the situation; so he didn't want to disturb her (…)"*

Service User 5 described a change from the unpredictability of an emergency situation to the stability of a home:

"The thing is though, without them, I wouldn't know where I'd be, 'cause they took me into their home (…) and my Mam used to move about into different houses and all that, and I came here 'cause I was like a sort of emergency respite."

Carer 5 elaborated on this by explaining:

"She's never had the safe home; she's never known from one day to the next whether they might be moved on to the next place, and in doing so whether it's going to be in a rush, or whether it's not – and half of her stuff's going to be left behind."

And similarly to other experiences, Carer 5 described Service User 5's development from a provision of security and safety:

"When [Service User 5] first came to us, she was extremely nervous; no confidence; had constantly been told she couldn't do this, she couldn't do that; as time went on, we discovered she could do all these things. The biggest thing that we support [Service User 5] with is confidence; ability; overcoming her shyness (…)"

Carer 4 felt strongly about security and predictability being maintained in their absence:

"And I'm very lucky, 'cause if I do go on holidays (…) I like [Service User 4] to stay here (…) so my sisters... they've all been through the family placement training (…) so if I go away, they come (…) so nothing's taken away, so he can feel secure (…)"

And Carer 6 described how they feel Service User 6 has benefitted from having a 'secure base':

"(…) She's benefitted, I think; she's - yeah, I think the growth – watching her grow – and she's secure enough to do that. I think that's another benefit."

The **provision of a 'secure base'** as a **CHRACTERISTIC OF THE SERVICE USER/CARER RELATIONSHIP** was also demonstrated by participants' experiences of maintaining contact at times of separation via the use of mobile phones and iPads. It refers back to and overlaps with the proximity-seeking behaviour of participants described as an aspect of the **differentiated relationship** (section 3.5.1.). In addition to this, Carer 1 described how they felt when separated from Service User 1:

"Oh, he's on your mind (…) Just like your baby (laughs), it's still there, you don't forget about them. You're still worried about them when they're not there sort of thing (…) you just get so attached to them, you can't switch off, you know, you just can't, it wouldn't be normal, I don't think, if you did."

The majority of participants also described missing the relevant other when away from them and this was often expressed through affectionate reunions following separation as Carer 2 described:

"(…) when we go and pick him up after we've been away for respite, the welcome we get is just fantastic! He hugs, and hugs, and hugs you."

3.5.4.2. The provision of a 'safe haven'

All service user participants had a shared experience of being able to rely on their Adult Placement carers for emotional and psychological support. This was most often described as turning to them for comfort, support and reassurance at times of distress or threat. For example, Service User 5 reported:

"Well I do talk to her. I worry about anything. And [Carer 5] advises me."

And when asked if they get upset or worried, Service User 2 said:

"Oh they'd [carers] be round you (…) the last time I had a bust out right I was er, [Carer 2] came round and hugged me and said 'be quiet now, come on, it's all over now'."

The researcher also noted that when Service User 2 said Carer 2's words, there was a distinct change in their tone from a generally rather loud tone to a softer, calmer one reflecting their carer's actual words. This was interpreted as a way of self-soothing through their repetition of Carer 2's words and tone of voice. This change in tone was also distinct from other changes in tone of voice, for example, a change from an upbeat, happy tone when answering questions about Service User 2's current placement to a much more serious tone when asked about previous accommodation. This was accompanied by the shaking of their head and holding their head down which was interpreted as an expression

through body language of how they felt when not having access to a **'safe haven'.** Such feelings may not have been able to have been expressed in words.

Service User 3 demonstrated an understanding of their carer as a **'safe haven'**, but they expressed how they continue to find it difficult to turn to their carer for support:

> *"It does feel difficult [to think about his sisters], but then, I keep it inside of me without telling anyone. And I should tell [Carer 3] because she is here for me."*

However, they also acknowledged that their carer would be there to help them and would…:

> *"…most probably talk it through with me. But she found out and then we talked and then (…) We're still talking about it now. I'm still talking about it."*

A number of the experiences described demonstrated sensitive and responsive support for service users within the relationship, including: building confidence in the relationship to be able to turn to the carer for support; being included in family activities but also being mindful of service users' preferences; being sensitive to needs associated with age, life cycle and loss; the management of dynamics between service users; the implementation of consequences in response to behaviour; and the recognition of psychological and emotional needs, understanding them, and ongoing support to regulate emotions.

Service User 1 described receiving *"comfort"* from his carer when he feels sad and Carer 1 demonstrated a sensitive understanding about how she supports Service User 1 at times of distress:

> *"We'll talk to him, find out what the problem is, and see if there is anything I can do, give him a hug (laughs), he finds it difficult but he does like it if I give him a hug, you know (…) Emotionally it's hard for him to show emotion in that way."*

Responsive support was also experienced by Service User 2 who felt that Carer 2 could tell if he is upset:

"They come to me (…) When I have a cry now and again. I couldn't stop crying (…) Well when he come and says 'alright Service User 2, it's all finished now', and they do help me a lot. I feel better then."

Again, the researcher noted a change in Service User 2's tone when repeating Carer 2's words. Service User 2 went on to explain that when they previously lived in a homeless shelter *"there was no [Carer 2]"*.

3.6. SUPERORDINATE THEME 3: "FAMILY"

A third superordinate theme that emerged from the data analysis is **"FAMILY"**. Incorporated into this is the **integration into the family**, **family dynamics**, and **family changes and coping**. Many of the aspects of the superordinate theme **"FAMILY"** are unique to Adult Placements and, therefore, overlap with the concept of it as **a different model of care.** One of the outcomes of Adult Placement is that it often results in service users having the opportunity to experience ordinary family life. In the majority of cases, this was described as the best thing about Adult Placement.

3.6.1. Integration into the Family

All participants had a shared experience of the **integration into the family** and this was demonstrated by the many descriptions of spending time with the family, and being part of special occasions. However, the process and levels of integration into the Adult Placement families differed for service users. Some service user participants felt a sense of belonging, as Service User 3 described when asked what the best thing was about their Adult Placement:

"Having the biggest family. What I've got now. I belong here (…) being part of the family (…) It feels good (…) Just being part of it."

Service User 6 also portrayed a sense of belonging when they said:

"I always felt like I known them. Forever"

And Service User 1 referred to themselves as part of the family:

> *"And they take me on holiday. And I see the grandchildren. I'm part of the family now."*

Carer participants also considered service users as members of their families, as Carer 2 reported:

> *"(…) Well, it's family. They're not clients, they're family – and that's the way we've always worked together, you know. It's family."*

Being part of the family also meant service users taking on a role within the family i.e. son/daughter, or grandparent. This was described by all carer participants and appeared to have contributed to the **integration into the family**. Service users were less likely to attribute roles to themselves but did describe carers, other family members, or other service users, in positions of a traditional family. For example, similarly to other participants, Service User 6 talked about their foster siblings as *"brothers and sisters".*

Service User 5 also described both their fellow service user also living permanently with their carer, and their carer's own children (now adults) as siblings and described having *"bonded"* with them. However, they also acknowledged *"I know they're not my family".* This was interpreted as them feeling integrated into the family but also feeling different to them, still in some ways, an outsider. They described a desire to be closer to them later in her narrative but was hesitant about how **integrated into the family** they could actually be:

> *"I'd like to spend most of the time with them [the family] but I don't want to push too far and get in the way (…) I want to bond with them but I don't want to push too far. I don't want to be overpowering to them."*

This is different to Service User 6's experience, who feels so integrated that they refer to their Adult Placement carers as *"Mum"* and *"Dad".* Carer 6 explained this further and expressed the view that this would not be usual practice. They acknowledged that this was a potential difficulty and there was some uncertainty as to how to respond although they were respectful of Service User 6's decision:

> *"(…) in [Service User 6]'s case, we've almost become surrogate parents (…) [Service User 6]'s sort of 'morphed' into one of our family. She's very loved by all of our family*

119

members, who she's treated as part of her family (…) and she refers to us as Mum and Dad (…) But that was a bit of a dilemma, because, you know (…) but it was her choice, so I'll go with that."

Carer 4 offered their view on Service User 4 as part of the family:

"(…) 'cause the way I sort of look at him (…) [Service User 4]'s like my granddad who has come to live with us! (…) And I would - the support I would give my grandfather I've sort of given to [Service User 4]."

Carer 4 went on to describe a defining moment for them that signified Service User 4's integration into the family:

"(…) I think the highlight for me, of it all, is when my brother asked [Service User 4] to come to his wedding (…) and for [Service User 4] to be sitting on the table with us, and especially with me, and my family, and my cousins, and my aunties and stuff (…) and laughing and enjoying every moment, and being part of the community, and part of - of life, really."

Carer participants also reflected on what it means to be a family. Their concept of what a family is has also likely supported their ability to invite and integrate service users into their families to evolve a new family 'norm'. For example, Carer 6 expressed the following view:

"She's [service user] very much part of our family (…) she's valued as part of our group of people. You don't have to be blood family, it doesn't have to be a blood relationship, does it, to be a family - you decide to live together. We're a group – we're a family. And that's what we are."

Carer 3 described how Service User 3's integration into the family was different to what they thought it would be:

"I thought it would be completely different. I thought that is going to be more of a "work" thing; and then (…) after him being here for some time (…) it's like part of the family really (…) he likes to say to people he's my foster son (…) he sees us as a family; but because he's included in everything he is just like another sibling to them (…) it's just like having another child."

120

3.6.2. Family Dynamics

Being **integrated into the family** meant that all participants had a shared experience of **family dynamics** with the Adult Placement family and, for some, a continuation and evolution of family dynamics with service users' families of origin. There were both positive experiences and more challenging aspects described. Therefore, **family dynamics** emerged as a subordinate theme to the superordinate theme **"FAMILY".**

Compatibility was an important concept raised by carer participants in relation to a matching process for service users and carers. This refers back to the process of **building relationships and rapport** in section 3.5.2. But in addition to the matching process, some participants described compatibility challenges and adaptation. For example, Carer 1 expressed the view that having Service User 1 as part of the family has changed them and described how they have adapted to fit in with the family:

> *"I suppose looking at it selfishly I've changed Service User 1 to fit in with us I suppose because that's how we live as a family but without meaning to. But then some of his ways weren't good (laughs), you know, but he seems quite happy with that, to fit in with us if you like."*

Carer 5 described how it took some time for Service User 5 to understand the family dynamics in their household but how with support they have come to appreciate them:

> *"(…) we tend to rib each other quite a bit (…) that's just what families do, don't they?! But [Service User 5] found that very difficult (…) she had no comprehension – of someone saying a remark in fun."*

Another aspect of the **family dynamics** was service users' experiences of relationships with other family members. This was supported by the carers' narratives, as Carer 2 described:

> *"My dad, as I said, comes over most evenings for a meal (…) he's [service user] good with Dad (…) they know Dad's quirky, and they work around that, and it's just not an issue for them. He loves going over to Paul's sisters' [other carer] - he loves it over there; they've got a boxer, and he loves that dog. He's got a good relationship with them."*

121

All participants shared experience of support received from the wider family network and there was a sense of reciprocated care with the Adult Placement family as Service User 6 illustrated:

> "I care about all of them [family]. I care for everyone. They care about me."

Carer 6 described how the family dynamics have changed but that family life has become more enriched with Service User 6 as part of it:

> "Well, for one, she's a female, which changed the dynamics of our family group `immensely – hugely! (…) I think it's enriched our family; we're all - we're just a family (…) we all enjoy her (…) so we benefit from her; from - from being loved really."

One of the more challenging aspects to the **family dynamics** was the management of dynamics between service users where carers offered a permanent placement to more than one service user. Examples included, supporting services users to understand the individual needs of others, and negotiation of support. Carer 4 provided one example of this:

> "(…) there's another gentleman living here as well (…) that was a big thing because (…) although [Service User 4]'s older than the other gentleman, [Service User 4]'s more able... so [Service User 4] would say "Oh, let me make a cup of tea now" and I'd say "[Service User 4], if you don't mind, leave Gareth do what he can do, because otherwise he's not (…) the skills he's learnt are not going to be met."

Another **family dynamic** that was shared by the majority of participants was the relationships and contact with the families of origin. There were both positive aspects and more challenging experiences which required the carer's support. Service User 3 had no contact with their family of origin but identified the importance of their sisters from their family of origin:

> "They're still in my heart and I can't forget them."

Service User 2 felt differently about their siblings:

"To tell you the truth, he's not around anymore, he's in the box, gone. I don't see my other two brothers (…) He's alright my brother-in-law, but when we were at the funeral, he said 'keep in contact', but he hasn't bothered since. Both of them never bothered (…) I don't miss them at all."

Service User 6 had positive experiences of relationships with their family of origin; however, Carer 6 described a stronger bond with the Adult Placement family:

"(…) she is interested in her family members (…) she does show that she cares about 'em, but I wouldn't say it's as loving as she is with us (…) it is very important to her that she sees them, but the bond is different here (…) she'll take the Christmas presents up now, she'll spend some time, and she'll come away. She's very happy to come away, you know."

This is a very different description of Service User 6's separation from their family of origin to the earlier description of the idea of being separate from their Adult Placement carer if they were to go to respite.

For some carers, relationships with families of origin were experienced as more challenging and alliances have taken time to be built, as Carer 5 expressed:

"I think challenges... I think top of the list would be the fact that her family (…) at the beginning, were not happy with her moving out (…) and we had a few problems to start off with. But as things have gone on, and we've actually got quite a good little thing going with her Mum at the moment (…)"

Despite challenges faced, what was clear from the participants' experiences was the commitment of the families to the service user. This was demonstrated by carers' accounts of the service user being wanted by the family; working through difficult times together; and as one carer, Carer 6, said *"It's a way of life, now. It's not a job".*

Carer 1 also demonstrated commitment to the service user by finding a way through the challenges that arise. They reported:

"(…) we're so attached to him now (…) I wouldn't part with him for the world."

3.6.3. Family Changes and Coping

The final subordinate theme derived from the notion of **"FAMILY"** emerged from participants' shared experiences of **family changes and coping.** This is in reference to how the Adult Placement families responded and coped to changes either within the Adult Placement family or the families of origin. Changes experienced included loss, bereavement, marital separation and moving house, some examples of which have already been present in the quotes in previous sections. Loss and bereavement was experienced either within the Adult Placement family or the service user's family of origin. Service users' shared the experience of being supported by Adult Placement families through changes.

One example was Service User 6's experience of multiple bereavements and their acknowledgement of support from their carer:

> *"(…) Sometimes I feel upset, see, my foster brother who was living here, last Christmas, he passed away (…) we talk about it, together (…) My Mum passed away as well, and my grancha as well."*

For one family, experiences were shared within the family and the service user was included in the process of bereavement, as Carer 6 reported:

> *"We laugh together, we cry together, and we row together. That's it. It's a family, you know."*

Another example of support from the Adult Placement family as a means of coping with change was described by one carer who felt strongly that the service user should continue to have their needs met following the separation with their spouse:

> *"When my husband left; I thought, "What's he [service user] thinking? Is he thinking he's going to miss out now?" But I've actually put things in place where I've got one of the men that works with me (…) he takes him out on a Thursday evening (…) he loves sport – all sports (…) and I purposely wanted to find a man to do it, so he could have that "boyish" time, you know?"*

124

The examples of **family changes and coping** highlighted from the service users' experiences are those that are experienced by all families and although challenging and upsetting at times appear to be part of the experience of an ordinary family life.

3.7. SUPERORDINATE THEME 4: PERSONAL AND PROFESSIONAL ISSUES (CARERS ONLY)

The final superordinate theme was derived from the carer participants' data analyses only. It is included in the results as the researcher considers it to contain significant themes that further support the understanding of the service users' experiences of Adult Placements. They are also related to broader systemic issues that have a potential impact on service users' relationships with their carers. Carer participants had shared experiences of **PERSONAL AND PROFESSIONAL ISSUES** in relation to the provision of Adult Placements. Such issues consider the **relationship with the team**, **important factors for the carer role**, **rewards and benefits**, and **challenges and dilemmas**.

3.7.1. Relationship with the Team

All carer participants had a shared experience of a **relationship with the Adult Placement Team**. Carers identified positive experiences of individual workers and felt that they were committed to and knew the service users and the Adult Placement families well. Of most significance was the carers' experience of the teams' commitment, availability and responsiveness, echoing **CHARACTERISTICS OF THE SERVICE USER/CARER RELATIONSHIP.** The teams are representative of a 'secure base' and 'safe haven' for the Adult Placement carers, a necessary model of support for the carers' **provision of a 'secure base' and 'safe haven'** for service users.

Carer 3 didn't feel that they had any needs for which they required support from the Adult Placement team; however, they valued their availability. Knowing that *"you can just ring them anytime"* was enough for them to feel they had a place to go to, a **'safe haven'** should they require support. When they had required support in the past they also valued the team's responsiveness. This was an experience shared by all carer participants.

Carer 6 felt that the service users were very well supported by the team, that they had a good working relationship with them, and valued feedback they received:

> "(…) the scheme is good and the support we get from the scheme is good (…) I have such a good relationship, particularly with the worker that we have now – who is on the other end of the phone – and when you do get exasperated, or there's something that you need to discuss, or you need that extra bit of support yourself, she's there. So when you've got support of that nature, it makes it easier, doesn't it? (…) You're not on your own"

Carer 5 used the notion of **"FAMILY"** to describe the support they felt both them and the service users have from the team:

> "(…) it's like a big family type thing, even for the office!"

Carer 5 stressed further that it is the knowledge of the availability of the team that is why the system works:

> "(…) it's knowing that I've got people that I can talk to (…) I think that's why it works; because you know that you've got people at the other end of a line that will come out and see you if you've got any problems."

Carer 2 described why they thought the system works:

> **"**I believe it works because they're committed to what they're actually doing. Because you can't work in a scheme environment like this, and the philosophy behind it and stuff, if you're just doing it as a job. And all the people that I've actually worked with (…) they've all believed in what they're actually doing, and I think that sums it up, really."

One carer had previous experience of a more difficult relationship with a team but in relation to a service user for whom they no longer provided a placement. Interestingly, although they felt that the support from the team for the current service user was available and responsive, they had not felt this for the other service user, and subsequently the placement had come to an end due to a change in service user and family needs and a difference in the support available to the carer.

3.7.2. Important Factors for the Carer Role

All carer participants described **important factors for the carer role** that they brought to their work with service users. The caring role was often embedded across generations of the family and they had a shared experience of previous caring roles prior to offering an Adult Placement. Personal and professional experience meant that they had an understanding of the individual needs of the client group and there was a shared belief that there was a *"type of person"* suited to the job. For example, Carer 5 described how Adult Placement had been recommended to them:

> *"(…) I suppose people saw that in me before I started doing this, and said "you'd be perfect for this job" (…) and you're either that type of person, or you're not!"*

Carer 4 also described important factors such as acceptance, tolerance and an understanding of people's needs:

> *"(…) it's being tolerant, and accepting things. But not only that, there's at - at the end of the day, it's like – [Service User 4] has got a learning disability as well, isn't it (…)"*

Participants also described personal values in their narratives which they believed were **important factors for the carer role**. This included enabling others, as Carer 2 described:

> *"I think I look at my role, really, as an "enabler" – enabling the people that we have living with us to lead active and fulfilled lives within the community, and within a family setting."*

And Carer 4 described valuing others:

> *"I've seen my nieces and nephew value other people, yeah (…) I think – 'cause of Mum – I think we've always sort of had a way of treating people, because, you know, seeing Mum go through what she went through, and stuff like that - so yeah, I think we value people."*

3.7.3. Rewards and Benefits

In addition to some of the rewards and benefits already discussed within other sections, the carer participants reflected on a number of **rewards and benefits** for both service users and carers in offering an Adult Placement. Some highlighted a positive experience and others some personal and practical benefits.

Carer 2 described their experience as:

> *"(…) it's just fun – it's real fun, you know"*

They also compared the quality of service they provide to previous employment and reflected on their ability to advocate for service users as a benefit for them:

> *"I saw this, really, as working in an environment that I know – i.e. my home – and (…) you can give 100% (…) The quality is completely different (…) So I find working in this environment far more rewarding – far more rewarding (…) I'm able to advocate for them; I'm a firm believer in advocating; if I know that they want something, and they're unable to actually voice it themselves, I'm quite capable of doing that – more than capable."*

Carer 4 said *"it just works"* and described mutual benefits for service users and carers of skill development:

> *"I think it's given me a wonderful experience, really, to appreciate other people as well. You know - 'cause sometimes we can take things for granted."*

Carer 4 also reflected on the rewards of feeling like you're 'doing something':

> *"(…) when [Service User 4] has got a smile on his face, and he's more than contented, and I just think, 'well I'm doing something'."*

The notion of 'doing something' was also important to Carer 3 when reflecting on how they have benefitted from offering an Adult Placement:

> *"(…) he has helped me, and he doesn't even understand that he has; that has been a massive benefit for me (…) I just feel good that I'm doing something for somebody."*

Other carer participants described a sense of satisfaction from observing the changes for service users. Carer 1 felt it was the *"doing of the caring"* that they most enjoy and described a sense of achievement seeing the service user's achievements. Carer 5 also reported seeing a difference as a reward for offering an Adult Placement:

> *"(…) you get so much back! Because you see the difference! (…) that's what we get out of it (…)"*

3.7.4. Challenges and Dilemmas

In addition to specific challenges and dilemmas raised when discussing the **CHARACTERISTICS OF THE SERVICE USER/CARER RELATIONSHIP** and **"FAMILY"**, challenges and dilemmas associated to the **PERSONAL AND PROFESSIONAL ISSUES** that have a potential impact on service users' experiences of Adult Placements were highlighted by carer participants.

The majority of carer participants had a shared experience of evolving with the changes to service provision and legislation, for example, the role of Adult Placement carer changing to incorporate the title of 'landlord', and service users as 'tenants'. The impact of such changes on carers included an increase in paperwork and participants had different responses to this. Carer 5 reflected on this and talked about acceptance to change:

> *"(…) I think people that have been with Adult Placement way back; I think they find that really difficult, because they've never had to deal with all this paperwork before. Whereas I kind of came into it when it was starting to build – the paperwork – so I've kind of just gone with the flow (…) you've got to go with the times (…) that's the way everything is nowadays; you've got to have everything in place, just in case."*

Carer 4's narrative raised a tension inherent within the concept of Adult Placement as a model of service. They and other carers shared concerns about getting the balance right between being part of a family and maintaining professional responsibility:

> *"I think the way I look at it, there's like - you know a weighing scale, so you've got to sort of get the right weights on both sides, and sort of measure where your role is; because, yes, it's family placement; but at the end of the day you've still got a code of practice; you've got a care of duty as well; and there is lines that are not meant to be*

crossed, you know - especially with [Service User 4] - I'm doing his medication, I'm doing his finances, I'm looking at his well-being as well. If I don't put a professional head on as well, none of those needs might be met"

Carer 6 also reflected on this. They expressed strong beliefs and raised important questions for services:

"(…) you are really responsible for somebody's life. But the overall responsibility remains with the authority. But they're with you, day in and day out (…) and we are a family – family first, not business (…) I could do it as a business, and I could run this like a tight ship, but I don't know how much independence - they would have a different type of independence, perhaps. But would it be as safe? Would it be as caring and would they feel as valued? I don't know (…)"

Despite the challenges experienced by carers and the potential impact of these on service users' experiences of Adult Placements, with support from the teams, carers worked hard to integrate changes and minimise the impact on individuals.

3.8. SUMMARY

Four superordinate themes were derived from the data analysis:

- The Function of Adult Placements
- Characteristics of the Service User/Carer Relationship
- "Family"
- Personal and Professional Issues (Carers Only)

The first three superordinate themes focused on the service users' experiences of Adult Placements and their relationships with their carers, and considered both the service user and carer perspectives. The final superordinate theme was derived from the analyses of the carer interviews only, but raised concepts that impacted on the service users' experiences and relationships with carers. Each of these superordinate themes consisted of further subordinate themes.

In summary, it appeared that the service user experience of Adult Placement meant a positive change for individuals, the opportunity to part of a family, and to be included in all aspects of ordinary family life. For most participants, integral to this experience were the relationships with carers and such relationships reflected the attachment needs of the individuals. In most cases, carers also considered themselves attachment figures in their individual relationships with service users and identified specific factors associated with the Adult Placement carer role. Integral to their experience were their relationships with the Adult Placement teams which reflected some of the attachment needs associated with the service user/carer relationship.

Most service users had been involved in the decision-making process to move to an Adult Placement. Key concepts underpinning the themes included the uniqueness of Adult Placements as a model of service for people with learning disabilities, the notion of family, and what this meant for all participants. There was a shared experience of 'Normalisation', opportunities, improvement in quality of life and relationships for all service user participants. Carers also had a shared experience of rewards and benefits alongside some challenges and dilemmas relevant to service users, carers, families and services.

CHAPTER 4 – DICUSSION

4.1. CHAPTER OVERVIEW

This final chapter aims to provide the reader with an understanding of how this study adds to the current knowledge base and how it may, therefore, influence the direction of future research and clinical practice. The results will be summarised and findings discussed in relation to existing literature and relevant psychological theory. The clinical and service implications will then be addressed, followed by an examination of the methodological strengths and limitations of the study. Finally, implications for future research are outlined, and conclusions of the research presented.

4.2. RESEARCH FINDINGS IN RELATION TO EXISTING LITERATURE

The overall aim of this study was to investigate the experiences of adults with learning disabilities living in long-term Adult Placements, drawing upon the perspectives of service users and carers. The researcher identified a small number of studies that have examined Adult Placements, most of which have not focused on the service user perspective and have not attempted to integrate findings with psychological theory. Therefore, this study adds significantly to the evidence base. The analysis of the data from the current study has provided four superordinate themes which will now be discussed. For ease of reading and to ensure consistency with the results section, **SUPERORDINATE THEMES** are written in bold and are capitalised, and **subordinate themes** are written in bold and lower case.

4.2.1. The Function of Adult Placements

THE FUNCTION OF ADULT PLACEMENTS was a superordinate theme that emerged from service users' and carer participants' accounts of Adult Placements. This theme was important because it highlighted a number of aspects demonstrating the uniqueness of the service model and provided a rich past and present context for understanding the meaning of Adult Placements for service users.

A different model of care described by participants reflected the 'ordinary' nature of Adult Placements. However, the concept of being 'ordinary' should not be underestimated as participants described highly flexible, person-centred support which enabled service users to share in the 'ordinary' daily lives of families. This was different to service users' previous experiences of care and reflects the central aims and objectives of Adult Placement schemes outlined in policy and guidelines (SCIE, 2005), namely, to live a normal life in the community and to share in the daily life of the Adult Placement carer. Service users tended to differentiate Adult Placements in concrete terms which support findings of previous studies that have included the views of service users (McConkey *et al.,* 2004). Carer participants also considered Adult Placement as **a different model of care** when compared to their experience of providing support for other people in other contexts.

All participants' accounts outlined a variety of opportunities that service users had been given as a result of living in Adult Placements, including access to work, college, leisure and social activities. The **opportunities** described reflected the principal aim of **'normalisation'** and O'Brien's five service accomplishments: community presence, choice, competence, respect and participation (O'Brien & Tyne, 1981). They also highlighted positively valued roles within society which can contribute to decreasing the stigmatisation of people with learning disabilities and to creating a positive image within society (Wolfensberger, 1972). All participants were able to describe how they came to be living in their Adult Placements, but there were differences across the sample in relation to the extent of their choice and their inclusion in the decision-making process.

A further theme derived from participants' accounts, which also demonstrated the impact of **'normalisation' and opportunities** on the lives of services users in this study, was the **improvement in quality of life and relationships**. The positive changes that participants' had experienced through living in an Adult Placement fits well with a number of core life domains that are central to the quality of life (Felce, 1997; Perry & Felce, 2003). This provides support from the service user perspective relating to previous research findings that have suggested this type of provision is able to provide excellent opportunities for maximising the quality of life for people with learning disabilities (Joshua, 2012). This is also consistent with evidence showing that community-based housing enables more

independence, inclusion and choice (DoH, 2012) and that such options are of greater benefit than those involving larger institutions (McConkey, 2007). However, the researcher uses the term 'independence' with caution. Within the current study, carer participants associated Adult Placement as **a different model of service** with *"a different type of independence"*, a type that is characterised as safe and caring, and where service users feel valued. This reflects emotional development through life, described by Holmes (1993) as 'mature dependence', rather than independence, and supports Bowlby's argument that even fully mature and autonomous adults benefit from seeking and receiving care from others (Bowlby, 1988).

Improvements in social relationships for service users were described by participants and such experiences contributed to changes for service users such as increased confidence and the experience of more freedom. Such changes were attributed by participants to their support received from carers which was possible due to being supported within **a different model of care.** This provides evidence to suggest that it is via relationships that people with learning disabilities can grow, learn and develop. This is consistent with service statements such as those proposed by Clegg and Lansdall-Welfare (2010) that call for creating, enhancing or improving relationships to be at the heart of all a service does. The findings from the current study also reflect previous research findings that have highlighted the invaluable role of the support staff within the context of facilitating the personal development of service users (Stimpson, 2009).

The continuity of relationships within Adult Placements was another factor highlighted by participants which contributed to service users' experiences of the **improvement in social relationships** whilst differentiating it from other models of service. This is most relevant to long-term Adult Placements. Service users' accounts of their previous experiences of support reflected the temporary nature of other service models. Carers' accounts compared staff turnover in other models of care with the continuity of relationships that were possible in long-term Adult Placements. The nature of such relationships developed within Adult Placements, their permanency and continuity, may protect service users against the emotional pain of repeated separations and losses identified in previous research within other models of service such as residential care (Mattison & Pistrang, 2000).

4.2.2. Characteristics of the Service User/Carer Relationship

Several **CHARACTERISTICS OF THE SERVICE USER/ CARER RELATIONSHIP** were described by participants and highlighted the significance and meaning that their relationships held. Some of the relationship characteristics reflected attachment dynamics which appears to support Bowlby's notion of the presence of attachment bonds throughout the life cycle (Bowlby, 1979).

Service users described the **differentiated relationship** that they had with carers and the closeness within the relationship, which was also supported by the outcomes of the relationship circle exercise. The service user perspective mirrors the closeness to service users described by Adult Placement carers in previous research (Joshua, 2012). Service users in the current study also distinguished the relationship with carers from relationships to members of their family of origin or previous caregivers. It was clear that, within the dyads, the relationships had a unique quality as perceived by the service users and carers, and that they had come to regard each other as a 'differentiated and preferred individual' in attachment terms (Bowlby, 1979). This is also consistent with Stimpson's (2009) findings with similar relationship dyads in residential care.

The current study also supports the presence of mutual 'affectional bonds' identified by Stimpson (2009). Such affectional bonds are thought to underpin attachment relationships throughout the lifespan (Salter Ainsworth, 1993). This was demonstrated by service users' and carers' proximity-seeking behaviour. Proximity to carers was maintained by a variety of methods, including a choice not to access respite and the use of communication devices to maintain contact whilst separated from carers. Separation was also characterised by emotional responses felt by service users when attending respite and the continued worry about service users that carers described.

Relationship building and rapport was another **CHARACTERISTIC OF THE SERVICE USER/ CARER RELATIONSHIP** highlighted as important to the participants and to the service users' experiences of Adult Placement. The building of relationships was described as a process, the speed of which differed amongst pairs, but all participants identified aspects of

compatibility that appeared integral to the relationship and to the ongoing connection. Such characteristics are considered to reflect the quality of relationships and affectional bonds that had developed. It was clear that getting on well together was extremely important to the service users' experiences of Adult Placement and this supports Hall's (2010) argument that people with learning disabilities share with the rest of humanity a yearning to belong, and to be in relationships with other persons.

Availability, involvement, feeling loved and cared for were all key experiences for service users associated with their Adult Placements. **Availability and involvement** was recognised by service users and this, again, differentiated the relationships they had with carers from other relationships in their lives. Service users valued knowing that carers were *"always there"* for them. Such characteristics are consistent with the quality of caregiving provided by a **'secure base'** in attachment theory. **Feeling loved and cared for** was a mutual experience for service users and carers and was evident through descriptions that showed the mutuality of affect, ideas and activities. Such aspects have been determined to reflect quality of relationships in previous research (Damen *et al.*, 2011).

A **CHARACTERISTIC OF THE SERVICE USER/ CARER RELATIONSHIP** that emerged from the participants' accounts and which relates to a key theme in attachment theory was the **provision of a 'secure base' and 'safe haven'.** The notion that the relationship provided a 'secure base' for service users was characterised by participants' descriptions of stability, predictability, safety and security from which growth, development and exploration occurred. The provision of a 'safe haven' was characterised by participants as service users being able to rely on carers for emotional and psychological support. In particular, it was important for service users to know that they could turn to carers for comfort, support and reassurance at times of distress or threat, and carers were responsive and sensitive to service users' emotional and psychological needs. Furthermore, participants also described examples of carers' attunement to the needs of service users and their availability to contain emotional and behavioural responses. Such concepts are fundamental to the ability of a caregiver to provide a 'secure base' and have featured most prominently within descriptions of infant/ caregiver attachments which prioritise the needs of the child. In this

context the caregiver serves as the attachment figure, provides security and protection from the child, but does not receive this in return (Rutter, 1995).

The findings from the current study were partly consistent with Stimpson's (2009) findings that although participants experienced mutual affection and reciprocation of practical aspects of support, there was a clear distinction between the roles of support staff and service users in terms of providing psychological and emotional support. In previous research, staff are identified as the attachment figure within the relationship, as they are in the current study. Also, a reversal of roles was not identified as they might be within other forms of adult attachments such as romantic partners and close friends. The current study, therefore, provides further support of a unidirectional nature of service user/ carer relationships as they appear to reflect adult attachments conceptualised within professional contexts such as client/ therapist relationships (Salter Ainsworth, 1993).

There were some examples in the current study where carers highlighted the emotional and psychological support provided by service users when carers experienced life changes. However, carers' descriptions of such occasions included their belief that service users were not necessarily aware of the role that they had played in supporting carers. Service users did not identify themselves as attachment figures for carers although they described responsibilities in the home and a sense of pride in relation to this. It may, therefore, be more appropriate to consider such support within the context of **"FAMILY"**, in particular, **family changes and coping**, rather than an attachment-related experience. Due to the service users' **integration into the family** within Adult Placements, the professional context transcends into a personal one in which service users have an opportunity to provide emotional and psychological support for family members and are able to do so due to their secure base within their attachment relationships with carers. Such support may be demonstrative of growth and the personal development of service users but it does not require them to be temporarily 'stronger and wiser' as it would be if such support were to be considered as that of an attachment figure. If this were the case, it would have the potential to leave the service user uncertain about their own 'secure base' and 'safe haven', which could potentially be detrimental to their emotional and psychological well-being (Mikulincer & Shaver, 2007).   A reversal of roles within attachment relationships is,

therefore, unlikely to be favoured within a service user/ carer relationship within Adult Placement, despite the more personal context within which the service user is supported in comparison to other models of care.

4.2.3. "FAMILY"

"FAMILY" was a superordinate theme that emerged from participants' accounts and is comprised of a number of subordinate themes. For service users, the experience of Adult Placement meant the opportunity to be part of a family and was also deemed the best thing about Adult Placement. Integration into the Adult Placement family was experienced by all service users to a greater or lesser extent and service users' experiences of **integration into the family** was characterised by a sense of belonging. Again, this echoes the notion that adults with learning disabilities share with the rest of humanity a yearning to belong, and to be in relationships with others (Hall, 2010). This often meant that service users perceived carers and other family members in roles of traditional family members, for example, mother, father, sisters, brothers, etc. This was either explicitly recognised within the family or was implicitly assumed. The findings are consistent with previous research undertaken within other models of care that demonstrated that residents thought of care workers as surrogate family members which provided them with a strong sense of being cared about (Moses, 2000). Carers in the current study also considered service users as family members, e.g. son, daughter or grandparent, but the personal context of the relationship was different to that which carers had expected.

Inclusion into the Adult Placement family did not exclude other aspects of service users' lives such as their families of origin. For service users, being part of a **"FAMILY"** meant experiencing **family dynamics** within the Adult Placement and, for some, a change in dynamics with their families of origin. Service users' accounts described building relationships with other Adult Placement family members, reciprocated care and support, and an experience that was difficult at first for some individuals. There were both positive and negative experiences of **family dynamics** with service users' families of origin. Carers again highlighted compatibility as an important factor and, for some, dynamics within the Adult Placement family and with the family of origin had been challenging at times. However, commitment to the service users meant that challenges were worked through

which provided service users with experience of coping with adversity. Carers' accounts also suggested that their families were enriched from having service users **integrated into the family** and that other family members benefitted from the experiences too.
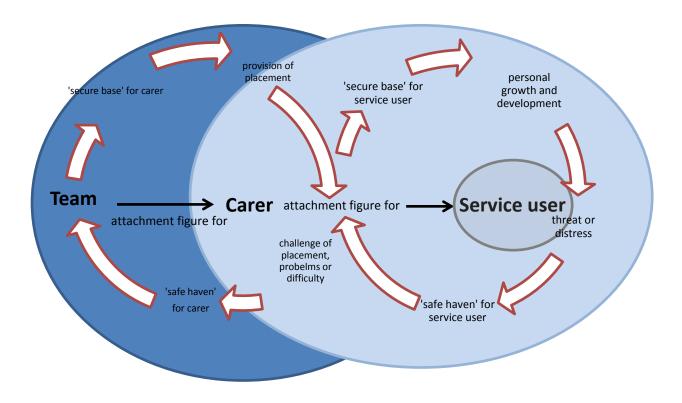
Service users' experiences of **"FAMILY"** also meant being involved in **family changes and coping** in relation to the Adult Placement family or the family of origin. Participants' accounts described service users being supported by Adult Placement carers through loss, bereavement, marital separation and moving home. Such examples are those experienced by all families and, although they may be challenging and upsetting, they appear to be part of the experience of an 'ordinary' life.

4.2.4. Personal and Professional Issues for Carers

The final superordinate theme was derived from the carer participants' accounts only. **PERSONAL AND PROFESSIONAL ISSUES FOR CARERS** highlighted themes that are pertinent to understanding the service users' experiences of Adult Placements. They also relate to further systemic issues that have a potential impact on service users' relationships with carers.

All carer participants suggested that their **relationship with the Adult Placement team** and positive experiences of individual workers contributed to their ability to provide placements. Carers experienced team members as committed, available and responsive which echoes their commitment, availability and responsiveness to service users. The current study, therefore, tentatively suggests that Adult Placement teams and individual members are representative of attachment figures for carers in that they provide a **'secure base' and safe haven'** to support the carer in their attachment role for service users. This is a second example in the current study of a unidirectional adult attachment conceptualised within a professional context. Figure 4.1 provides a diagrammatic representation of the adult attachment relationships highlighted in the current study and the **provision of 'a secure base' and 'safe haven'** (adapted from Marvin *et al.,* 2002).

Figure 4.1: Diagrammatic Representation of Unidirectional Adult Attachment Relationships within a Professional Context

The diagram above represents two attachment relationships operating within this service context. The team are representative of an attachment figure for carers, as the carers are representative of attachment figures for service users. Carers' accounts demonstrated that they had few support needs in relation to providing placements for service users. However, the teams' availability was valued by carers who attributed the success of the system to the commitment and availability of the team.   When carers had required support, the responsiveness of the teams was also highly valued. In the current study, an example of a carer's account of the team not representing a 'secure base' and 'safe haven' and the placement then breaking down, may provide further support for the hypothesis presented here.

All carer participants described **important factors for the carer role** that meant that they had an understanding of the individual needs of service users. Previous personal and professional experience appeared to give carers confidence in their ability to undertake and enjoy the role. This supports previous research findings that highlight previous experience

as a principal motivating factor for providing a placement (Joshua, 2012; McConkey *et al.*, 2005). Personal values were also identified as an **important factor for the carer role** including valuing and enabling others.

Carers also spoke passionately about the individuals they supported and it was clear that they enjoyed caring for the service users placed with them. Carers' accounts reported mutual **rewards and benefits** for service users and carers, including enjoyment, satisfaction, skill development and a sense of achievement. These findings are consistent with previous research (McConkey *et al.,* 2005). Carers' accounts also described the reward of feeling like they were 'doing something' which has previously been suggested to contribute to the motivations to provide a placement (Joshua, 2012).

Carers' accounts also identified a number of **challenges and dilemmas** that had a potential impact on service users' experiences of Adult Placements. An inherent tension within the Adult Placement model of service is the personal/ professional dilemma, particularly in the context of changing legislation and guidelines. Individual perceptions of how personal or how professional a placement may be will impact on a service user's experience of the placement. Carers' accounts described different positions on a personal and professional continuum, but all described the importance of getting the balance right. The balance required is likely to be one that meets the needs of the service user, the carer and the family as a unit.

4.3. THEORETICAL IMPLICATIONS

There has previously been limited application of attachment theories with regard to understanding service users' experiences, perspectives and relationships within the field of learning disability. The importance of relationships between service users and carers were highlighted in the current study and explored from an attachment theoretical perspective. This contributes to a deeper psychological understanding of how these factors influence service users' experiences.

A number of themes have emerged from the findings, and these appear to fit well with the literature on 'normalisation', quality of life, and attachment theory as it is conceptualised and applied in adulthood. The ways in which the emerging themes relate directly to the literature have been addressed in the previous section. However, to summarise, the findings of the current study suggest that attachment dynamics exist in relationships between adults with learning disabilities and Adult Placement carers. More specifically, affectional bonds can develop and carers appear to fulfil a role of attachment figure for service users living within Adult Placement contexts. The current research suggests that the nature of the attachment bond is unidirectional in that carers appear to serve as attachment figures for service users, but this role relationship is not reciprocated. This is consistent with previous research that examined the attachment relationships between adults with a learning disability and support staff within a supported living context (Stimpson, 2009). The findings also suggest that Adult Placement teams and individual team members can serve as attachment figures for carers, as carers' accounts identified similar qualities within their relationships with team members to those that were identified by service users within their relationships with carers. The nature of these relationships was also perceived to be unidirectional. These are important findings in theoretical terms, as they are consistent with the way in which attachment has been conceptualised within professional relationships (Salter Ainsworth, 1993), despite the very personal family context within which Adult Placements are provided.

The researcher acknowledges the potential to draw on other alternative theoretical models to interpret the data in the current study. The literature reviewed in Chapter One also demonstrated a limited range of studies investigating attachment relationships in adults with learning disabilities. Therefore, there is currently little theoretical or empirical support for the findings and the links that have been made to attachment theory are of a tentative nature.

4.4. CLINICAL AND SERVICE IMPLICATIONS

The study produced a number of themes that are important to service users' experiences of Adult Placement. The findings raise a number of clinical and service implications. Concepts

such as 'normalisation' and ideas associated with it have been present in the learning disability literature informing service policy and guidance for some time. Services for people with learning disabilities have much improved. However, the problematic issues that led to such developments continue to persist for some people with learning disabilities. Unfortunately, this continues to be demonstrated by widespread failure to design, commission and provide services which give people the support they need close to home, and which are in line with well-established best practice (DoH, 2012). Therefore, concepts such as 'normalisation' and 'quality of life' continue to be relevant for people with learning disabilities and to be an important focus for services. The findings from the current study provide evidence from the service user perspective that Adult Placement is a model of service that can provide adults with learning disabilities the opportunity to lead 'ordinary' lives where relationships with others are valued as a priority. Adult Placement is not a dominant model of service at present, but it is perhaps more effective for some individuals and has been demonstrated to be a cost-efficient alternative to more traditional models of care (Shared Lives Plus, 2013).

Service users' accounts of their experiences highlight the value they placed on their relationships with carers. In previous research examining the carers' perspective, Adult Placement carers were found to be fundamental in meeting the psychological and emotional needs of service users they support. Joshua (2012) demonstrated that carers clearly 'cared about', rather than simply 'cared for' service users. In the current study, the views of adults with learning disabilities support the previous findings, as it was clear that service users felt 'cared about' rather than simply 'cared for' by carers. This study provided further evidence to support the view that Adult Placement carers fulfil the role of attachment figures for service users with a learning disability. It is also consistent with accounts of service users and support staff within the context of supported living (Stimpson, 2009). Therefore, in addition to providing practical care and support, the current study also supports the view that a fundamental aspect of the Adult Placement carer role is meeting the emotional and psychological needs of service users they support.

Carer participants in the current study reported feeling well supported by Adult Placement teams. However, for some, the attachment bonds with service users and some of the more

emotionally challenging aspects of the relationships appeared to come as a surprise, suggesting that carers were unprepared for this, despite the training they had received, the rigorous recruitment and selection processes, and the vital matching process for service users and carers. This raises implications for increasing the awareness and understanding of Adult Placement carers regarding their potential function as attachment figures for people with learning disabilities. This, in turn, may enhance carers' skills to carry out complex aspects of their role and to improve quality of life and emotional well-being of service users. Clinical psychologists may be best suited to raise awareness of the emotional needs of adults with learning disabilities via training, supervision and consultation when working alongside carers and teams. This could be most effectively facilitated in collaboration with service users and carers to highlight the ways in which secure attachment relationships can be developed and maintained. Findings from the current study could also inform training and consultation for carers and teams for specific cases where attachment issues and relationship difficulties are present. This has been demonstrated to be effective in previous clinical interventions (Clegg & Lansdall-Welfare, 1995). Systemic models of practice such as Network Training (Jenkins & Parry, 2006) provide one way to facilitate increased awareness and understanding of an individuals' needs with the entire network of support. The findings of the current study relating to the Adult Placement team member's potential role of attachment figure for carers could also inform service level training, supervision and consultation. This highlights the importance for on-going commitment of team members to service users and carers and requires on-going commitment at an organisational level for a quality of service to be maintained.

Service users' and carers' accounts of the service users' experiences of Adult Placement also raised an important consideration for respite care. Difficulties associated with accessing regular respite for carers and the benefits associated with regular breaks, namely continuity of the provision of high quality care, were previously identified by Joshua (2012). In the current study, respite and spending time away from carers was considered from a service user perspective and suggests that some service users find separation from carers difficult. For participants, this was manageable, as service users who attended respite appeared to understand the need for carers to have a break and reunions were acknowledged by carers as important moments for service users. In some cases, service users declined to access

144

respite, however, such arrangements also suited carers. Understanding service users' needs from an attachment perspective may contribute to their ability to manage separation from carers in order that distress of separation is minimised for service users and that carers are able to access the break they require. Sharing the findings of the current study with service users, carers, teams and relevant others may provide some good practice examples that can be followed mare widely.

4.5. METHODOLOGICAL STRENGTHS AND LIMITATIONS OF THE STUDY

4.5.1. Methodology and Design

The review of the available literature in Chapter One highlighted the lack of research examining service users' experiences of Adult Placement and the relationships that exist between adults with learning disabilities and Adult Placement carers from the service user perspective. This study, therefore, was intended to provide a rich and detailed exploration of service users' experiences of Adult Placement and their relationships with their carers. A qualitative methodology was deemed appropriate for this study as it allowed the researcher to explore participants' experiences and provide a rich and in-depth account of the meaning they attributed to these experiences. A thorough phenomenological analysis of the interviews with service users and carers fitted the aims of the study. A variety of qualitative methodologies could have been selected, but IPA was considered the most appropriate as it is committed to the detailed examination of human lived experience (Smith *et al.,* 2009). Other methodologies may have yielded different findings.

An assumption of IPA is that qualitative data can tell us something about people's involvement in and orientation towards the world and/ or about how they make sense of this (Smith *et al.,* 2009). Data, therefore, needs to be reasonably rich and participants are required to reflect on their experiences. This presents potential difficulties when conducting research with individuals with cognitive impairment and limited verbal abilities, such as adults with a learning disability. However, data that is not rich does not necessarily have less value (Beail & Williams, 2014). Attention has been paid to methodological challenges such as gaining informed consent; establishing a sensitive and facilitative research relationship; and methods and approaches to data collection (Nind, 2008). The

researcher in the current study took measures to address the above challenges and to overcome the barriers associated with the chosen methodology.

An information sheet was prepared for service users to ensure that they were fully informed about the study. Information was presented as clearly as possible, using a minimum number of words and removal of ambiguous or complex phrases. The researcher made sure that all methodological and ethical issues were covered. Symbols and pictures were also utilised to ensure that the information was as accessible as possible for service users. Similar considerations were applied to the consent forms, the semi-structured interview schedule, and debriefing forms. Detailed information sheets were also provided to the carers to ensure that they were also fully informed about what would be required of their own participation. Initial contact with participants was made by Adult Placement team members who knew service users well and who were able to go through the information with them in the context of an existing relationship.

The researcher allowed plenty of time for service users to consider their participation in the research and engaged in warm-up conversations with each service user prior to starting the interview. This aimed to minimise the power imbalance within the research relationship, to build rapport with participants and to increase the service user's confidence in making an informed decision about their participation. Consent was reaffirmed and service users were reminded of the voluntary nature of participation to try and minimise the risk of acquiescence.

This study adds to a growing body of literature that challenges a traditionally held view that there are some groups of people who are unable to express their views and perspective (Lloyd *et al.,* 2009). The inclusive design of the research and strategies used to address methodological challenges of using IPA with adults with learning disabilities are considered to be strengths of the study. Furthermore, the researcher engaged with service users and carers at different stages of the study to promote a collaborative approach and principles of inclusive research (Walmsley & Johnson, 2003). For example, service users and carers were consulted when developing initial ideas and two pilot interviews with service users were conducted when developing the interview schedule. Carers were also interviewed to add an

additional perspective to understanding the service user experience. However, the researcher was keen to maintain a service user focus and mindful not to allow the carer perspective to dominate. For this reason service users were interviewed first. Areas of importance to service users could then inform aspects of the carer interview in order to gain a carer perspective on what service users highlighted as most prominent. The design of the study is, therefore, consistent with policy requirements to include service users in the evaluation of their own care (Young & Chesson, 2006).

4.5.2. Recruitment and Sample

The sample was recruited from two different Adult Placement schemes providing Adult Placements for service users with a learning disability. This sample was deemed suitable to explore the phenomenon of Adult Placement and relationships with carers experienced by adults with a learning disability. However, the sample may have been less representative as it only involved individuals who had the cognitive ability and communication skills to provide informed consent and to engage with the research process. The sample was, therefore, likely to be biased towards individuals with a mild/ borderline learning disability despite the different levels of ability evident in the sample. Recruitment also relied upon support from the Adult Placement schemes and these might have chosen participants who were more likely to give positive views of services. This may have increased the possibility of a biased sample. Service users who were experiencing difficulties within their placements may have been less likely to have been identified as participants.

The sample size of 12 (comprising of six interview dyads) was considered appropriate in terms of the research aims and methodology. However, this is a relatively small sample in comparison to traditional quantitative methods, which require large numbers of participants for statistical analysis and generalisation of the results to the wider population. It is, therefore, questionable whether the findings of the current study are useful in understanding service user experience of Adult Placement and attachment relationships with carers, other than those included in the study. In IPA a small sample is recommended to allow for sufficient examination of both shared and individual experiences (Smith *et al.,* 2009). Therefore, conclusions are drawn from the study, but generalisations to the wider learning disability population should be made with caution, particularly as it is only a small

minority of the learning disability population who access Adult Placements. The improved quality of life and types of relationship experienced by the population in this study represent a small homogenous sample of people with learning disabilities, and the researcher does not therefore claim that the findings can be generalised beyond the present sample.

4.5.3. Data Collection and Analysis

The aim of the research was to collect data about service users' experiences of Adult Placement with a particular focus on the relationships developed with Adult Placement carers. Two interview schedules were developed in line with these aims and included open-ended questions to encourage participants to influence the direction of the interview. Although this study has considered the findings within the context of attachment theory, the word "attachment" was not used by the researcher during the interviews to avoid leading participants.

The researcher included a balanced set of questions focused on positive and negative experiences within the semi-structured interview schedules and ensured that a balance of questions were asked within the interviews. The researcher was keen to make sure that participants had the opportunity to discuss more difficult aspects of their experiences whilst remaining aware of the potential for acquiescence when obtaining the views of people with learning disabilities. Despite this, the results of the study, whilst acknowledging some challenges, demonstrate mostly positive experiences for service users and carers, with very few negative aspects of Adult Placements evident in the data. This may be representative of a biased sample and/ or the challenge of acquiescence. However, service users gave very clear answers in relation to what they did and did not like about their placements and what challenges they had experienced. The researcher felt that service users were giving well-formed opinions and not just being passively compliant in the process. All service users also chose to participate in interviews separately from carers and they were aware of the confidential nature of the interviews which hopefully enabled service users to speak freely about their experiences of Adult Placements and their relationships with carers and family. However, service users were aware of the interviews with carers that were to follow and

had been required to consent to this. This is likely to have had some impact in what was discussed within the service users' interviews.

The depth and quality of the interviews may have been compromised by a number of factors including: participant contact consisting of a one-off meeting which may have impacted on the quality of rapport within the research relationship; and more directive prompts required to support service users' participation in interviews which may have resulted in more researcher-led interviews than is desirable in IPA. Even so, coherent results were produced which provided a rich set of superordinate and subordinate themes, illustrated by quotes from the data (Elliott *et al.,* 1999). Therefore, findings are grounded in examples and demonstrate similar and contrasting experiences of individuals.

During the transcribing process, all identifying information was changed to protect confidentiality. One drawback of this is the loss of richness in relation to participant background information. The researcher was struck by the powerfulness of people's stories and past experiences which is potentially lost via the research process. However, she was also aware of the need to remain focused on the research aims and objectives which concerned the present experience of individuals.

An area of strength in the current study was the use of reflexivity on the part of the researcher.   Reflexivity is important so that the researcher may understand and communicate their own role and bias during data collection and analysis (Elliott *et al.,* 1999; SURE, 2013). The researcher for the current study provided a position statement to inform the reader of personal and professional background influences, and these were also acknowledged and reflected upon by the researcher within a research diary and bracketing interviews (Rolls & Relf, 2006). A description of the IPA procedure used and samples of the analysis process are provided to ensure transparency. Such measures allow the reader to evaluate the results within the context of the researcher's position and the methodology used.

4.5.4. Ensuring Quality

The study was conducted according to ethical standards and included informed consent and confidentiality. This is demonstrated by the University ethical approval obtained. Measures were taken throughout the course of the research to ensure quality in the conduct and the analysis of the study (Elliott *et al.,* 1999). Results were interpreted and analysed only by the researcher. However, credibility checks were undertaken to ensure that the analysis remained as close as possible to the participants' accounts. This included reviewing the themes that emerged from the analysis with research supervisors. There was no input from participants into the analysis, or commentary on the findings due to time restrictions, but researcher reflexivity tasks were carried out in order to enhance the validity of the findings. The review of the literature also situated findings and feedback was sought from supervisors on drafts of chapters.

4.6. IMPLICATIONS FOR FUTURE RESEARCH

The researcher acknowledges that the current study is a relatively small and preliminary one, but its findings suggest a number of possibilities for further research. Due to the small sample size, it is not possible to generalise the findings of the current study. Therefore, revisiting this area of investigation using larger sample sizes may further develop our understanding of the experiences of service users living in Adult Placements. Other populations are also supported within Adult Placements, including vulnerable adults, people with physical disabilities and people experiencing mental health difficulties. Research with alternative participant groups may identify other significant aspects of experiences of Adult Placement, not just those that were identified for people with a learning disability. It would also be interesting to consider the findings of the current study with other groups to consider types of relationships between Adult Placement carers and people with different needs. The current study also led to a number of hypotheses about the relationships between carers and Adult Placement team members. To explore this further, obtaining professionals views would be an important aspect.

The current study explored the experiences of adults with a learning disability who were relatively able due to the inclusion criteria applied and the need for participants to have

capacity to consent to participation in the research process. It may, therefore, be useful to investigate the experiences of people with more severe learning disabilities who may or may not engage in verbal communication. There are also some instances where Adult Placements have not worked, and investigating service users' and carers' experiences of such instances may provide valuable information about the emotional and psychological needs of adults with learning disabilities.

The current study considered service users' experiences of their relationships with carers using attachment theory to understand the types of attachment relationships experienced within Adult Placements. Further research identifying attachment styles of service users or attachment representations of carers may provide useful and interesting information about the impact of how these styles affect relationships between adults with learning disabilities and Adult Placement carers. This may highlight important factors for services, as attachment representations of professional caregivers have been suggested to modify the impact of interventions to improve caregiving (Schuengel *et al.,* 2012). However, further research is also required to identify appropriate tools that enable closer and more detailed examination of attachment issues in relation to attachment style and the applicability of such measures to the broad range of people with learning disabilities (Larson, *et al.,* 2011).

4.7. CONCLUSIONS

The current study has explored in-depth the experiences of adults with a learning disability living in Adult Placements with a specific focus on their relationships with Adult Placement carers. Previous research has examined the motivations and experiences of providers of Adult Placement or has touched on some of the benefits for service users. However, this appears to be the first study to explore in-depth service users' experiences of long-term Adult Placements. The findings have highlighted important themes that represent the meaning associated with Adult Placement for service users, namely an improvement in quality of life and the opportunity to be part of a family. This supports the suggestion that small community-based support options are advantageous for adults with a learning disability.

Relationships developed between adults with learning disabilities and Adult Placement carers have been found to closely resemble attachments as they are conceptualised in adulthood. The study, therefore, has provided evidence to support the view that Adult Placement carers represent attachment figures for people with learning disabilities. Such findings are consistent with research undertaken within a supported living context that examined relationships between service users and support staff. The findings also suggest that a similar attachment relationship may exist between Adult Placement carers and team members; and that these relationships support carers to develop and maintain their relationships with service users.

The findings have highlighted a number of clinical and service implications, which primarily relates to the enhancement of training and supervision to increase awareness and understanding of the emotional and psychological well-being of people with learning disabilities in relation to their attachment needs. Several directions for future research have also been highlighted.

REFERENCES

Abell, S., Ashmore, J., Beart, S., Brownley, P., Butcher, A., Clarke, Z., et al. (2007). Including everyone in research: the Burton Street Research Group. *British Journal of Learning Disabilities*, *35*, 121–124.

Adshead, G. (1997). Psychiatric staff as attachment figures. Understanding management problems in psychiatric services in light of attachment theory. *British Journal of Psychiatry, 172*(10), 64-69.

Ahnert, L., Pinquart, M. & Lamb, M. E. (2006). Security of children's relationships with nonparental care providers: a meta-analysis. *Child Development,* 77, 664–79.

Ainsworth, M. D. S. (1989). Attachments Beyond Infancy. *American Psychologist, 44,* 709-716.

Allen, P., Pahl, J. & Quine, L. (1990). *Care Staff in Transition.* London: HMSO.

Allen, J. G., Coyne, L. & Huntoon, J. (1998). Complex posttraumatric stress disorder in women from a psychometric perspective. *Journal of Personality Assessment, 70,* 277-298.

American Association on Intellectual and Developmental Disabilities. (AAIDD, 2010). *Intellectual Disability: Definition, Classification, and Systems of Supports* (11th Edn). Washington DC: American Association on Intellectual and Developmental Disabilities.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th edition), DSM-V. Arlington, VA: American Psychiatric Publishing.

Antonsson, H., Graneheim, U.H., Lundström, M. & Åström, S. (2008). Caregivers' reflections on their interactions with adult people with learning disabilities. *Journal of Psychiatric and Mental Health Nursing, 15,* 484-491.

Arscott, K., Dagnan, D. & Kroese, B.S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *11(1),* 77-83.

Arscott, K., Dagnan, D. & Stenfert Kroese, B. (1999). Assessing the ability of people with a learning disability to give informed consent to treatment. *Psychological Medicine, 29*(6), 1367-75.

Atkinson, L., Chisholm, V. C., Scott, B., Goldberg, S., Vaughn, B. E., Blackwell, J. *et al*. (1999). Maternal sensitivity, child functional level, and attachment in Down syndrome. In J. Vondra & D. Barnett (Eds.) *Atypical Attachment in Infancy and Early Childhood. Monographs of the Society for Research in Child Development, Vol. 258* (pp. 45–66). Washington, DC: SRCD.

Baldwin, M. W. & Kay, A. C. (2003). Adult attachment and the inhibition of rejection. *Journal of Social and Clinical Psychology, 22,* 275-293.

Bank-Mikkelsen, N. E. (1980). Denmark. In R. J. Flynn & K. E. Nirsch (Eds.) *Normalization, social integration and community services* (pp. 51-70). Baltimore: University Park Press.

Barker, C., Pistrang, N. & Elliott, R. (2002). *Research methods in clinical psychology: an introduction for students and practitioners* (2nd edition). Chichester: Wiley.

Barr, O., McConkey, R. & McConaghie, J. (2003). Views of people with learning difficulties about current and future accommodation: the use of focus groups to promote discussion. *Disability and Society, 18*(5), 577-97.

Bartholomew, K. & Horowitz, L. M. (1991). Attachment styles among young adults: a test of four-category model. *Journal of Personality and Social Psychology, 92,* 226-244.

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

Beail, N. & Williams, K. (2014). Using qualitative Methods in Research with People who have Intellectual Disabilities. *J of Applied Research in Intellectual Disabilities, 27(2), 85-96.*

Bernard, S. (2004). *Adult Placement Counts: A Survey of Adult Placement Schemes in England.* The National Association of Adult Placement Services (NAAPS).

Bishop, F. L. & Holmes, M. M. (2013). Mixed Methods in CAM Research: A Systematic Review of Studies Published in 2012. *Evidence-Based Complementary and Alternative Medicine, 2013,* p. 1-12.

Bowlby, J. (1951). *Maternal care and mental health.* Geneva: World Health Organisation.

Bowlby, J. (1953). *Child care and the growth of love.* Harmondsworth, England: Penguin.

Bowlby, J. (1969). *Attachment and Loss*. (Vol. 1). New York: Basic Books

Bowlby, J. (1979). *The Making and Breaking of Affectional Bonds*. London: Tavistock

Bowlby, J. (1980). *Attachment and loss.* (Vol. 3). New York: Basic Books.

Bowlby, J. (1982). *Attachment and loss: Vol. 1. Attachment* (2nd ed.). New York: Basic Books. (Original ed. 1969).

Bowlby, J. (1988). *A secure base: Clinical applications of attachment theory*. London: Routledge.

Boxall, K. & Ralph, S. (2011). Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities, 39*, 173–180.

Brennan, K. A., Clark, C. L., & Shaver, P. R. (1998). Self-report measurement of adult romantic attachment: An integrative overview. In J. A. Simpson & W. S. Rholes (Eds.), *Attachment theory and close relationships* (pp. 46-76). New York: Guilford Press.

British Psychological Society (1991). *Mental impairment and severe mental impairment: A search for definitions.* Leicester: British Psychological Society.

British Psychological Society (2000). *Learning disability; definitions and contexts.* Leicester: British Psychological Society.

Brown, H. & Smith, H. (1992). Defending community care: can normalisation do the job? *British Journal of Social Work*, *22*(6), 685-693.

Buber, M. (1994). *I and Thou.* (German original 1923). Ludvika: Dualis Förlag AB.

Cambridge, P. & McCarthy, M. (2001). User focus groups and Best Value in services for people with learning disabilities, *Health and Social Care in the Community, 9*(6), 476-489.

Cameron, L. & Murphy, J. (2006). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities, 35,* 113–120.

Care and Social Services Inspectorate Wales (CSSIW, 2004). *The Adult Placement Schemes (Wales) Regulations.* Retrieved on 15 January 2015 from: http://cssiw.org.uk

Carnaby, S. (2005). *Learning Disability Today.* Pavilion Publishing (Brighton) Ltd.

Carnaby, S. (2007). *Learning Disability Today.* Pavilion Publishing (Brighton) Ltd.

Cassidy, J. (1999). The nature of the child's ties. In J. Cassidy & P. R. Shaver (Eds.) *Handbook of Attachment: Theory, Research, and Clinical Applications* (pp. 3–20). NewYork: Guilford Press.

CHANGE (n.d). *How to make information accessible: A guide to producing easy read documents*. Leeds: CHANGE.

Chaplin, R. (2009). Annotation: New research into general psychiatric services for adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research, 53*(3), 189-199.

Chappell, A. L. (1997). From Normalisation to Where? In L. Barton & M. Oliver (Eds.) *Disability Studies: Past Present and Future* (pp.45-62)*. Leeds: The Disability Press.

Clegg, J., & Lansdall-Welfare, R. (1995). Attachment and learning disability: a theoretical review informing three clinical interventions. *Journal of Intellectual Disability Research, 39*(4), 295-305.

Clegg, J., & Landsall-Welfare, R. (2010). From autonomy to relationships: productive engagement with uncertainty. *Journal of Intellectual Disability Research, 54*(1), 66-72.

Clegg, J. & Sheard, C. (2002). Challenging behaviour and insecure attachment. *Journal of Intellectual Disability Research, 46*(6), 503-6.

Cooper, M. L., Shaver, P. R. & Collins, N. L. (1998). Attachment styles, emotion regulation, and adjustment in adolescence. *Journal of Personality and Social Psychology, 74,* 1380-1397.

Marvin, R., Cooper, G., Hoffman, K. & Powell, B. (2002). The Circle of Security Project: Attachment-based intervention with caregiver-pre-school child dyads. *Attachment and Human Development, 4*(1), 107-124.

Crook, B., Tomlins, R., Bancroft, A. & Ogi, L. (2015). 'So often they do not get recruited': exploring service user and staff perspectives on participation in learning disability research and the barriers that inhibit it. *British Journal of Learning Disabilities* (Original Article). John Wiley & Sons Ltd.

Culham, A. & Nind, M. (2003). Deconstructing normalisation: clearing the way for inclusion. *Journal of Intellectual & Developmental Disability, 28*(1), 65-78.

Dagnan, D. (1997). Family Placement Schemes Offering Long-term Care for Adults with Learning Disabilities: A review of the evaluation literature. *Disability & Society, 12*(4), 593-604.

Damen, S., Kef, S., Worm, M., Janssen, M. J. & Schuengel, C. (2011). Effects of video-feedback interaction training for professional caregivers of children and adults with visual and intellectual disabilities. *Journal of Intellectual Disability Research, 55*(6), 581-595.

Department of Health (2001a). *Valuing People: A New Strategy for Learning Disability for 21st Century.* London: Department of Health.

Department of Health (2001b). *Nothing about us without us*. London: Department of Health.

Department of Health (2003a). *National minimum standards for adult placements*. London: Department of Health.

Department of Health (2003b). *Seeking Consent: Working with people with learning disabilities.* The Department of Health, Social Services and Public Safety: Belfast.

Department of Health (2005). *Independence, Well-being and Choice*. London: Department of Health.

Department of Health (2009). *Valuing People Now: a new three year strategy for people with learning disabilities – making it happen for everyone.* London: Department of Health.

Department of Health (2012). *Transforming Care: A national response to Winterbourne View Hospital.* London: Department of Health.

De Schipper, E. J., Riksen-Walraven, J. M. A. & Geurts, S. A. E. (2007). Multiple determinants of caregiver behaviour in child care centres. *Early Childhood Research Quarterly, 22*, 312–26.

De Schipper, J. C., Tavecchio, L.W. C. & Van IJzendoorn, M. H. (2008). Children's attachment relationships with daycare caregivers: associations with positive caregiving and the child's temperament. *Social Development, 17,* 454–70.

De Schipper, E. J., Riksen-Walraven, J. M. A., Geurts, S. A. E. & DeWeerth, C. (2009). Cortisol levels of caregivers in child care centres as related to the quality of their caregiving. *Early Childhood Research Quarterly, 24*, 55–63.

De Wolff, M. S. & Van IJzendoorn, M. H. (1997). Sensitivity and attachment: a meta-analysis on parental antecedents of infant attachment. *Child Development, 68,* 571–91.

Dozier, M., Chase Stovall, K. & Albus, K. E. (1999). Attachment and Psychopathology in Adulthood. In J. Cassidy & P. R. Shaver (Eds.). *Handbook of Attachment: Theory, Research, and Clinical Applications* (pp. 497-519). New York: Guilford Press.

Duncan, B., Miller, S. & Sparks, J. (2004). *The Heroic Client.* San Francisco: Jossey-Bass.

Elliott, R., Fischer, C. T. & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related research fields. *British Journal of Clinical Psychology, 39,* 7-10.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A. *et al.* (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal of Mental Retardation, 106*(5), 401-415.

Emerson, E. & Hatton, C. (2008). *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England.* Centre for Disability Research Report 8.

Emerson, E. & Hatton, C. (2011). *Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An Update.* Improving Health and Lives: Learning Disabilities Observatory.

Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S., Evison, F., *et al.* (2012). People with Learning Disabilities in England 2011. Improving Health and Lives: Learning Disabilities Observatory.

Feeney, B. C. (2004). A secure base: Responsive support of goal strivings and exploration in adult intimate relationships. Journal of Personality and Social Psychology, 87, 631-648.

Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research, 41*(2), *126-135.*

Felce, D. & Perry, J. (1999). Quality of life: Its definitions and measurement. *Research in Developmental Disabilities, 16*(1), *51-74.*

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beechams, J., *et al.* (2006). The Social Networks of People with Intellectual Disability Living in the Community 12 Years after Resettlement from Long-Stay Hospitals. *Journal of Applied Research in Intellectual Disabilities, 19*, 285–295.

Fraley, R. C. (2002). Attachment stability from infancy to adulthood: Meta-analysis and dynamic modelling of developmental mechanisms. *Personality and Social Psychology Review, 6,* 123-151.

Freedman, G. (2001). Editorial. Systemic practice within clinical psychology: why not? *Clinical Psychology, 3,* 4-7.

Gage, A. (1995). A profile of adult placement carers. *British Journal of Social Work, 25,* 635-646.

Gelder, M. C., Lopez-lbor, J. J. & Andreason, N. (2000). *New Oxford Textbook of Psychiatry* (1st edn). Oxford: Oxford University Press.

George, C., Kaplan, N. & Main, M. (1996). Adult Attachment Interview, unpublished manuscript, Department of Psychology, University of California, Berkeley (third edition), available at: www.ahealthymind.org/library/AAI%20Protocol.pdf

Gilbert, T. (2004). Involving people with learning disabilities in research: issues and possibilities. *Health and Social Care in the Community, 12*(4), 298-308.

Golding, K. (2007). Attachment theory, debate, controversy and hope. A clinician's perspective. *Attachment theory into practice.* Briefing paper no. 2. Leicester: The British Psychological Society.

Gorfin, L. & McGlaughlin, A. (2005) Listening to the disempowered. *The Psychologist*, *18(7),* 426-428.

Greenberg, M. T. (1999). Attachment and Psychopathology in Childhood. In J. Cassidy & P. R. Shaver (Eds.). *Handbook of Attachment: Theory, Research, and Clinical Applications* (pp. 469-496)*.* New York: Guilford Press.

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research, 54*(1), 48–57.

Hall, P. S. & Hall, N. D. (2002). Hiring and retaining direct care staff: after fifty years of research, what do we know? *Mental Retardation, 40,* 201-211.

Hanrahan, D. (2006). The influence of media and respondent characteristics on the outcome of a campaign to recruit host families for adults with learning disability. *British Journal of Social Work, 26,* 979-996.

Harlow, H. (1958). The nature of love. *American Psychologist, 13,* 673-685.

Hatton, C. (2012). In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine & J. Bromley (Eds.) *Clinical Psychology and people with learning* disabilities (2nd edition)*. Chichester: John Wiley & Sons Ltd.

Hazan, C. & Shaver, P. (1987). Romantic love conceptualized as an attachment process. *Journal of Personality and Social Psychology, 52*(3), 511-524

Hazan, C. & Zeifinan, D. (1999). Pair Bonds as Attachments: Evaluating the Evidence. In J. Cassidy & P. R. Shaver (Eds.). *Handbook of Attachment: Theory, Research, and Clinical Applications* (pp. 336-354)*. New York: Guilford Press.

Heidegger, M. (1962/1927). *Being and Time.* Oxford: Blackwell.

Henwood, K. & Pidgeon, N. (1992). Grounded theory. In G. Breakwell, C. Fife-Schaw, S. Hammond & J. A. Smith (Eds). *Research Methods in Psychology* (3rd edition). London: SAGE.

Hermsen, M. A., Embregts, P. J. C. M., Hendriks, A. H. C. & Frielink, N. (2014). The human degree of care. Professional loving care for people with a mild intellectual disability: an explorative study. *Journal of Intellectual Disability Research, 58*(3), 221-232.

Hirst, J. (2000). A Fresh Start. *Community Care* (31st May 2000).

Hollins, S. & Sinason, V. (2000). Psychotherapy, learning disabilities and trauma: new perspectives. *British Journal of Psychiatry, 176,* 32-36.

Holmes, J. (1993). Attachment theory: a biological basis for psychotherapy? *British Journal of Psychiatry, 163,* 430-438.

Husserl, E. (1931). *Ideas: General Introduction to Pure Phenomenology* (W. R. B. Gilson, Trans). New York: Humanities Press, Original work published 1913.

Jackson, R. (2011). Invited Review: Challenges of residential community care: 'the times they are a-changing'. *Journal of Intellectual Disability Research, 55*(9), 933-44.

Janssen, C. G. C., Schuengel, C. & Stalk, J. (2002). Understanding challenging behaviour in people with severe and profound intellectual disability: a stress-attachment model. *Journal of Intellectual Disability Research, 46*(5), 445-53.

Janssen M. J., Riksen-Walraven J. M. & van Dijk J. P. M. (2003). Contact: effects of an intervention program to foster harmonious interaction between deaf-blind children and their educators. *Journal of Visual Impairment & Blindness* 97, 215–28.

Jenkins, R. & Parry, R. (2006). Working with the support network: applying systemic practice in learning disabilities. *British Journal of Learning Disabilities, 34*(2), 77-81.

Joshua, L. (2012). *Adult family placements: the experiences of carers in learning disability services.* Unpublished dissertations: submitted in partial fulfilment of the requirement for the degree of DClinPsy at Cardiff University and the South Wales Doctoral Programme in Clinical Psychology.

Kerr, D. (2007). *Understanding Learning Disability and Dementia.* London: Jessica Kingsley Publishers.

King's Fund. (1980). *An Ordinary Life: comprehensive locally based residential services for mentally handicapped people.* London: King's Fund.

Larson, F. V., Alim, N. & Tsakanikos, E. (2011). Attachment style and mental health in adults with intellectual disability: self-reports and reports by carers. *Advances in Mental Health and Intellectual Disabilities, 5*(3), 15-23.

Leeds & York Partnership NHS Foundation Trust (2015). Image Bank downloadable content from: www.easyonthei.nhs.uk/all

Levin, E. (2004). *Involving service users and carers in social work education*. London: Social Care Institute for Excellence.

Lloyd, V., Gatherer, A. & Kalsy, S. (2009). Conducting Qualitative Interview Research With People With Expressive Language Difficulties. *Qualitative Health Research, 16*(10), 1386-1404.

Lynggaard, H. (2005). Issues across the life path: managing change, transition and loss. In S. Carnaby (Ed.) *Learning disability today* (pp.201-208)*.* Brighton: Pavilion Publishing.

Main M. & Solomon J. (1986) Discovery of an insecure-disorganized/ disoriented attachment pattern. In T. B. Brazelton & M.W. Yogman (Eds.) *Affective Development in Infancy* (pp.95–124). Norwood, NJ: Ablex.

Malekpour, M. (2007). Effects of early attachment on early and later development. *The British Journal of Developmental Disabilities, 53*(2), 81-95.

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *The Lancet, 358,* 483-488.

Mansell, J. (1996). The cost and quality of community residential care by NV Raynes, K Wright, A Sheill & C Pettipher. *Journal of Intellectual Disability Research, 40*(5), 482-483.

Mattison, V. & Pistrang, N. (2000). *Saying Goodbye: When Keyworker Relationships End.* London: Free Association Books.

McCarthy, M. (2005). Intimate lives: sexuality and people with learning disabilities. In S. Carnaby (Eds.) *Learning Disability Today.* Pavilion Publishing (Brighton) Ltd.

McClure, K., Halpern, J., Wolper, P. & Donahue, J. (2009). Emotion Regulation and Intellectual Disability. *Journal Of Developmental Disabilities, 15*(2), 38-44.

McConkey, R. (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disabilities, 51*(3), 207-217.

McConkey, R., McConaghie, J., Roberts, P. & King, D. (2004). Family placement schemes for adult persons with intellectual disabilities living with elderly carers. *Journal of Learning Disabilities, 8*(3), 267-82.

McConkey, R., McConaghie, J., Roberts, P. & King, D. (2005). Characteristics of people providing family placements to adult persons with intellectual disabilities. *BILD Publications, British Journal of Learning Disabilities, 33,* 132-137.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R. & Burton-Smith, R. M. (2006). '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), 191-203.

Mellows, K. (2012). *Employed Carers' Empathy Towards People with Learning Disabilities.* Unpublished dissertations: submitted in partial fulfilment of the requirement for the degree of DClinPsy at Salomons Christ Church University and the Canterbury Christ Church University for the degree of Doctor of Clinical Psychology.

Mental Capacity Act (2005). London: The Stationary Office. Retrieved 15 January 2015 from: www.legislation.gov.uk

Merleau-Ponty, M. (1962). *Phenomenology of Perception.* London: Routledge.

Mickelson, K.D., Kessler, R. C. & Shaver, P. R. (1997). Adult attachment in a nationally representative sample. *Journal of Personality and Social Psychology, 73,* 1092-1106.

Mikulincer, M. & Shaver, P. R. (2007). Boosting attachment security to promote mental health, pro-social values, and inter-group tolerance. *Psychological Inquiry, 18*(3), 139-156.

Minnis, H., Fleming, G. & Cooper, S-A. (2010). Reactive Attachment Disorder Symptoms in Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities, 23,* 398-403.

Moore, H. (2013). *The Experiences of Parents with Learning Disabilities Receiving Formal Support: The Interpersonal Context of Parenting.* Unpublished dissertations: submitted in partial fulfilment of the requirement for the degree of DClinPsy at Cardiff University and the South Wales Doctoral Programme in Clinical Psychology.

Moran, G., Pederson, D. R. & Krupka, A. (2005). Maternal unresolved attachment status impedes the effectiveness of interventions with adolescent mothers. *Infant Mental Health Journal, 26,* 231-249.

Moses, T. (2000). Attachment theory and residential treatment: a study of staff-client relationships. *American Journal of Orthopsychiatry, 70*(4), 474-90.

National Health Service and Community Care Act (1990). London: The Stationary Office. Retrieved 15 January 2014 from: www.legislation.gov.uk

National Institute for Clinical Excellence, (NICE, 2012a). Methods for the development of NICE public health guidance (3rd edition). Retrieved 3 March 2015 from: www.nice.org.uk

National Institute for Clinical Excellence, (NICE, 2012b). *Appendix G: Quality appraisal checklist – quantitative studies reporting correlations and associations.* In NICE: Methods for the development of NICE public health guidance (3rd edition). Retrieved 3 March 2015 from: www.nice.org.uk

Nind, M. (2008). *Conducting qualitative research with people with learning, communication and other disabilities: methodological challenges.* ESRC National Centre for Research Methods.

Nind, M. & Vinha, H. (2012). Doing research inclusively: bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities* (Original Article). John Wiley & Sons Ltd.

Nirje, B. (1980). *The Normalisation principle.* In R.J. Flynn and K.E. Nitsch (Eds.) *Normalisation, Social Integration and Community Services*. Austin: Pro-Ed.

O'Brien, J. & Tyne, A. (1981). *The Principle of Normalisation: A foundation for effective services.* London: Campaign for Mentally Handicapped People: Community and Mental Handicap Educational and Research Association.

Oliver, M. (1994). *Capitalism, disability and ideology: a materialist critique of the normalization principle,* paper presented at the conference 25 Years of Normalization, Social

Role Valorization and Social Integration: A Retrospective and Prospective View, University of Ottawa, May 10th-13th.

Orlinsky, D. E., Grawe, K. & Parks, B. K. (1994). Process and outcome in psychotherapy: Noch einmal. In A. E. Bergin & S. L. Garfield (Eds.) *Handbook of Psychotherapy and Behavior Change* (pp.270–376). New York: John Wiley & Sons.

Penketh, V., Hare, D. J., Flood, A. & Walker, S. (2014). Attachment in Adults with Intellectual Disabilities: Preliminary Investigation of the Psychometric Properties of the Manchester Attachment Scale-Third Party Observational Measure. *Journal of Applied Research in Intellectual Disabilities, 27,* 458-470.

Perry, J. & Felce, D. (2003). Quality of life and outcomes for people with intellectual disabilities living in staffed housing services: a stratified random sample of statutory, voluntary and private agency provision. *Journal of Applied Research in Intellectual Disabilities, 16,* 11-28.

Pianta, R. C. (1994). Patterns of relationships between children and kindergarten teachers. *Journal of School Psychology,* 32, 15–31.

Pockney, R. (2006). Friendship or facilitation: people with learning disabilities and their paid carers. *Sociological Research Online, 11*(3).

Prosser, H. (1999). An invisible morbidity? *Psychologist, 12,* 234-237.

Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experience: An introduction to Interpretative Phenomenological Analysis. *The Psychologist, 130*, 20-23.

Reinders, H. (2009). The importance of tacit knowledge in practices of care. *Journal of Intellectual Disability Research, 54*(1), 28-37.

Rodgers, J. (1999). Trying to get it right: undertaking research involving people with learning difficulties. Disabil Soc, *14,* 421–33.

Roeden, J. M., Maaskant, M. A. & Curfs, L. M. G. (2011). The Views of Clients with Mild Intellectual Disabilities Regarding their Working Relationships with Caregivers. *Journal of Applied Research in Intellectual Disabilities, 24*, 398-406.

Rolls, L. & Relf, M. (2006). Bracketing interviews: addressing methodological challenges in qualitative interviewing in bereavement and palliative care. *Mortality, 11*(3)*,* 286-305.

Royal College of Psychiatrists (2003). *Meeting the mental health needs of adults with a mild learning disability.* London: The Royal College of Psychiatrists.

Royal College of Psychiatrists. (2004). *Psychotherapy and Learning Disability.* London, The Royal College of Psychiatrists.

Rutter, M. (1995). Clinical Implications of Attachment Theory: retrospect and prospect. *Journal of Child Psychology and Psychiatry, 36,* 549-571.

Sable, P. (2007). Accentuating the positive in adult attachments. *Attachment and Human Development*. *9*(4), *361-374.*

Salter Ainsworth, M. D. S. (1993). Attachment and other affectional bonds across the life cycle. In C. M. Parkes, J. Stevenson-Hinde & P. Marris (Eds.). *Attachment across the life cycle* (pp. 33-51). New York: Routledge.

Salter Ainsworth, M. D. S., Blehar, M. C., Waters, E. & Wall, S. (1978). *Patterns of Attachment: A Psychological Study of the Strange Situation*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Sartre, J-P. (1956/1943). *Being and Nothingness.* New York: Washington Square Press.

Schore, A. N. (1994). *Affect Regulation and the Origin of the Self: The Neurobiology of Emotional Development.* New Jersey: Lawrence Erlbaum.

Schuengel, C., Kef, S., Damen, S. & Worm, M. (2012). Attachment representations and response to video-feedback intervention for professional caregivers. *Attachment & Human Development, 14*(2), 83-99.

Schuengel, C., Clasien, J., de Schipper, P., Sterkenburg, S. & Kef, S. (2013). Attachment, Intellectual Disabilities and Mental Health: Research, Assessment and Intervention. *Journal of Applied Research in Intellectual Disabilities, 26,* 34-46.

Shaping Our Lives (2003). Shaping Our Lives National User Network, Black User Group (West London), Ethnic Disabled Group Emerged (Manchester, Footprints and Waltham Forest Black Mental Health Service user Group (North London) and Service Users' Action Forum (Wakefield). *Shaping Our Lives – From Outset to Outcome: What People Think of the Social Care Services They Use.* York: Joseph Rowntree Foundation.

Shared Lives Plus. (2013). *Shared Lives/Adult Placement in Wales 2013*. Wales, Shared Lives Plus.

Shear, K. & Shair, H. (2005). Attachment, loss and complicated grief. *Developmental Psychobiology*, *47 (3)*, 253-267.

Sheard, C., Clegg, J. A., Standen, P. & Cromby, J. (2001). Bullying and people with severe learning disabilities. *Journal of Intellectual Disability Research, 41*, 407-415.

Sigelman, C. K., Budd, E. C., Spankel, C. L. & Schoenrock, C. J. (1981). When in doubt, say yes: acquiescence in interviews with mentally retarded persons. *Ment Retard, 19*, 53–55.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1,* 39-54.

Smith, J. A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research.* London: SAGE.

Smith, J. A. & Osborn, M. (2008). Interpretative Phenomenological Analysis. In A. Smith (Ed). *Qualitative Psychology: A Practical Guide to Research Methods.* London: Sage Publications.

Smith, P. & McCarthy, G. (1996). The Development of a Semi-Structured Interview to Investigate the Attachment-Related Experiences of Adults with Learning Disabilities. *British Journal of Learning Disabilities, 24*(4), 154-160.

Specialist Unit for Review Evidence (SURE, 2013). Questions to assist with the critical appraisal of qualitative studies. Available at: www.cardiff.ac.uk/insrv/libraries/sure/doc/SURE_RCT_Checklist_2013.pdf

Social Care Institute for Excellence, SCIE. (2005). *SCIE Guide 8: Adult placements and person-centred approaches.* Retrieved 14 April 2015 from www.scie.org.uk

Social Finance and Community Catalysts. (2013). *Investing in Shared Lives: A Social Finance report produced in partnership with Shared Lives Plus, Community Catalysts, Macintyre and RSA 2020 Public Services.* London: Social Finance Ltd.

Stiles, W. B. (1993). Quality control in qualitative research. *Clinical Psychology Review, 13,* 593-618.

Stimpson, A. (2009). *Attachment relationships between adults with learning disabilities and their support staff.* Unpublished dissertations: submitted in partial fulfilment of the requirement for the degree of DClinPsy at Cardiff University and the South Wales Doctoral Programme in Clinical Psychology.

Strnadová, I. & Cumming, T. M. (2013). Editorial. People with Intellectual Disabilities Conducting Research: New Directions for Inclusive Research. *Journal of Applied Research in Intellectual Disabilities.* John Wiley & Sons Ltd.

Stroebe, M., Schut, H. & Stroebe, W. (2005). Attachment and coping with bereavement: A theoretical integration. *Review of General Psychology, 9*(1), 48-66.

Tate, R. L., Mcdonald, S., Perdices, M., Togher, L., Schultz, R. & Savage, S. (2008). Rating the methodological quality of single subject designs and n-of-1 trials: Introducing the Single-Case Experimental Design (SCED) Scale. *Neuropsychological Rehabilitation: An International Journal*, 18(4), 385-401.

Test, D., Flowers, C., Hewitt, A. & Solow, J. (2004). Training needs of direct support staff. *Mental Retardation, 42*(5), 327-337.

Todd, S., Felce, D., Beyer, S., Shearn, J., Perry, J. & Kilsby, M. (2000). Strategic Planning and progress under the All Wales Strategy. Reflecting on the perceptions of stakeholders. *Journal of Intellectual Disability Research, 44,* 31-44.

Van IJzendoorn, M. H., Rutgers, A. H., Bakermans-Kranenburg, M. J., Van Daalen, E., Dietz, C., Buitelaar, J. K. *et al*. (2007). Parental sensitivity and attachment in children with autism spectrum disorder: comparison with children with mental retardation, with language delays, and with typical development. *Child Development, 78,* 597–608.

Vetere, A. & Dallos, R. (2003). *Working systemically with families: formulation, intervention and evaluation.* London: Karnac.

Walmsley, J. & Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present and Future.* London: Jessica Kingsley Publishers.

Waters, E. & Cummings, E. M. (2000). A secure base from which to explore close relationships. *Child Development, 71,* 164–72.

Watt, G. & Brittle, R. (2008). The influence of attachment on relationships in caring for people with learning disability. *Learning Disability Practice, 11*(2), 16-19.

Weschler, D. (2008). *Wechsler Adult Intelligence Scale (WAIS–IV)* (4th edn). USA: Pearson.

Welsh Assembly Government (2007). *Statement on policy and practice for adults with a learning disability*. Retrieved 15 January 2014 from: www.ldiag.org.uk

Welsh Assembly Government (2009). *One Wales, One Planet: The Sustainable Development Scheme of the Welsh Assembly Government.* Retrieved 15 January 2014 from: www.wales.nhs.uk

Welsh Assembly Government (2011). *Practice guidance on developing a commissioning strategy for people with a learning disability.* Retrieved 15 January 2014 from: http://gov.wales

Welsh Government (2011). *Sustainable Social Services for Wales: A Framework for Action*. Retrieved 15 January 2014 from: http://gov.wales

Welsh Assembly Learning Disability Advisory Group (2001). *Fulfilling the promises: proposals for a framework for services for people with learning disabilities.* Cardiff: National Assembly for Wales.

Welsh Office (1983). *The All Wales Strategy for the Development of Services for Mentally handicapped people.* Welsh Office, Cardiff.

Whitehead, S. (1992). The social origins of normalisation. In H. Brown & H. Smith (Eds). *Normalisation: A Reader for the Nineties.* London: Tavistock/Routledge.

Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in Theory.* Buckingham: Open University Press.

Willig, C. (2008). *Introducing Qualitative Research in Psychology* (2nd edn). McGraw Hill: Open University Press.

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

World Health Organisation (1992). *ICD-10 classification of mental and behavioural disorders: Clinical description and diagnostic guidelines.* Geneva: World Health Organisation.

Young, A. F. & Chesson, R. (2006). Obtaining views on health care from people with learning disabilities and severe mental health problems. *British Journal of Learning Disabilities, 34*(1), 11-19.

LIST OF APPENDICES

Appendix I: Full List of Search Term Variants Considered when Searching the Literature

Search terms in relation to the participant group:

Learning disab*	Intellectual disabilit*	Intellectual* Impair*
Mental* Retard*	Mental* Impair*	Developmental Disabilit*
Learning Impairment*	Cognitive Impairment*	Learning difficult*
Mental handicap*	Mental* subnormal*	Service user*

Search terms regarding service user experience of:

Experience*	Perspective
View*	Inclusive research
Service user involvement	

Search terms regarding Adult Placement/Care/Carer:

Service*	Adult Placement*	Adult Family Placement*
Shared living	Long term care	Community placement
Family care*	Foster care*	Staff*
Paid carer*	Foster placement*	
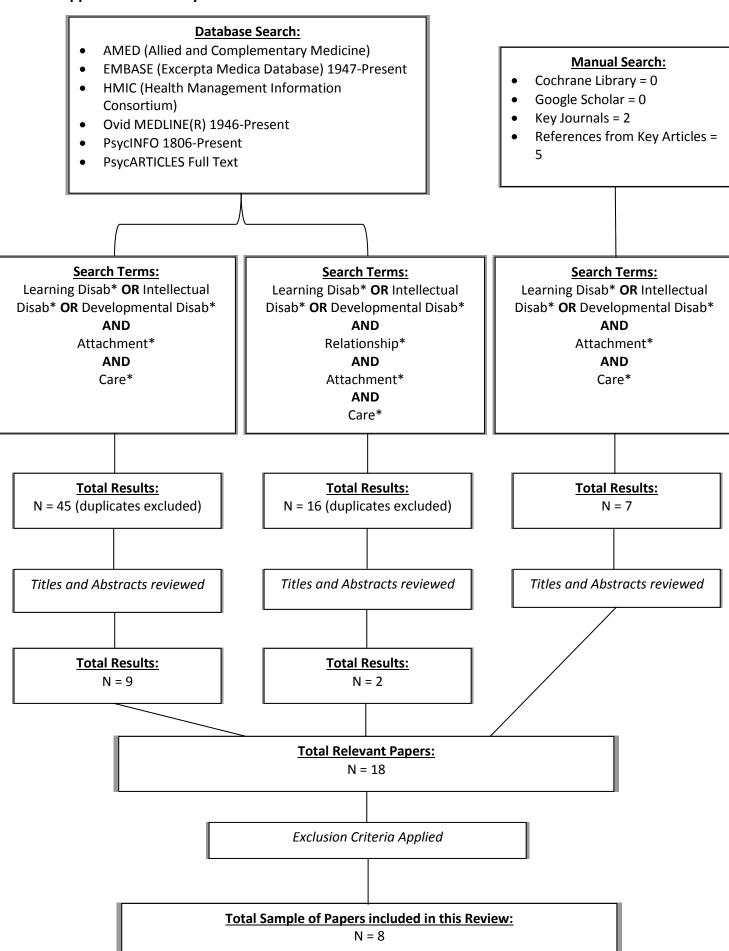
Search terms regarding attachment relationships:

Adult*	Attachment*
Relationship*	Bond*

Appendix II: The Systematic Review Search Process

Database Search:
- AMED (Allied and Complementary Medicine)
- EMBASE (Excerpta Medica Database) 1947-Present
- HMIC (Health Management Information Consortium)
- Ovid MEDLINE(R) 1946-Present
- PsycINFO 1806-Present
- PsycARTICLES Full Text

Manual Search:
- Cochrane Library = 0
- Google Scholar = 0
- Key Journals = 2
- References from Key Articles = 5

Search Terms:
Learning Disab* **OR** Intellectual Disab* **OR** Developmental Disab*
AND
Attachment*
AND
Care*

Search Terms:
Learning Disab* **OR** Intellectual Disab* **OR** Developmental Disab*
AND
Relationship*
AND
Attachment*
AND
Care*

Search Terms:
Learning Disab* **OR** Intellectual Disab* **OR** Developmental Disab*
AND
Attachment*
AND
Care*

Total Results:
N = 45 (duplicates excluded)

Total Results:
N = 16 (duplicates excluded)

Total Results:
N = 7

Titles and Abstracts reviewed

Titles and Abstracts reviewed

Titles and Abstracts reviewed

Total Results:
N = 9

Total Results:
N = 2

Total Relevant Papers:
N = 18

Exclusion Criteria Applied

Total Sample of Papers included in this Review:
N = 8

Appendix III: Extracts from Reflective Diary

28/11/13

So today I met with the TRAC group to discuss my research idea. I felt I had prepared well and was pleased I took the information sheet. The committee was extremely helpful but also appropriately challenging. They seemed pleased that I was undertaking a project interviewing adults with learning disabilities and there was a general surprise by all that I was the first trainee to approach them. They gave me some very useful feedback and things to consider. Some committee members felt that as I am the one carrying out the research it is not as inclusive as it could be if it were people with learning disabilities themselves doing the work. I need to have a think about that, I don't disagree with them but I am not sure what they were suggesting is possible for this purpose and within this timeframe. I realise I am using the systemic ideas to understand this, considering the different positions that are being expressed here. I also need to consult the literature about inclusive research, about the different types of research that might be considered inclusive.

11/04/14

I met with my research supervisors this week to discuss the proposal and ethics application. I received some really valuable feedback about my information sheets and semi-structured interview schedule. I now need to undertake a pilot interview – things seem to be progressing well.

25/11/14

Reflections following second service user and carer interview and when transcribing:
This service user interview, I fear, is an example of what my supervisor raised concerns about i.e. I was getting more monosyllabic answers from the participant and a focus on concrete, tangible aspects of the placement being the positive experience. I felt I was having to lead the interview, prompting, asking more questions, that I am now concerned were quite closed questions at times, but concrete for the service user. I found myself repeating a lot of what the participant said back to them to check out whether I had understood correctly. They appeared to understand what I was asking and no concerns were raised for me about their capacity to consent to this research, however, their expressive communication appeared limited despite the use of supporting pictures. I feel I need to discuss the interview with my supervisor so I will make a time to see her.

Despite this, I came away feeling like the participant had been given an opportunity to express their opinion and to talk about their experience. And my impression was that their quality of life is much

improved since they have lived in an adult placement. They appeared very thoughtful about my questions, and they were expressive in ways other than verbal language - their tone changed and they were expressive through their facial expressions and use of body language. They changed from an upbeat, happy tone when answering questions about their current placement to a much more serious tone when I asked questions about their previous accommodation. Also, when they talked about a family member with whom they had a difficult experience, they shook their head and held their head down which I interpreted as their expression of how they felt about this although they were less able to describe this in words. Also, when I asked about how their carer supported them when they were upset or worried, they described what their carer said and their tone of voice changed from quite a loud tone (generally) to a soft, calm voice, which reflected their carer's actual words. My main concern is that this is not captured in a transcript. I have tried to add in notes of where their tone of voice changed, however, I hope this can be an area of discussion. My feeling is that this gives insight into ways that the experiences of people who have limited verbal communication can be captured because it is most definitely being expressed by them. Whether this provides me with the 'quality of data' required for this purpose I am unsure. I return to the epistemological position about the meaning for the individual and this participant gave a very meaningful account of their experience, they just didn't have a lot of words to share it. Maybe something to look into the literature about and discuss.

17/12/14

I am not sure arranging the four interviews how I did so today was such a good idea. My concern of being late for the last two might have impacted on the quality of the first two interviews and then the second two were not as rich with information! As a consequence I feel rather frustrated. And yet again I have heard such powerful stories today. And how services have changed people's lives. I was also aware of some themes coming to mind following today's interview – something about family roles – the service users taking a family role i.e. child or grandparent. And also something about balance and the caring role. I've also been learning a lot about my own interactional style, interjecting at times when I could stay quiet!

06/01/15

So I have now completed and transcribed all of the research interviews. I feel partly relieved that the next stage is completed – first ethics, now data collection. However, I am also aware of some feelings of apprehension for the next stage. I seem to fluctuate between feeling confident that the data is rich enough for qualitative analysis but then I experience moments of panic that I might not

find any themes! I'm not sure I would have felt this had it not been questioned. My thinking has shifted, that richness of data is a potential difficultly when carrying out research with people with learning disabilities re: cognitive and language skills, however, it is what it is, and I can discuss this within the write-up. I am aware that my thoughts are being influenced by some of the acceptance-based theory we have been learning about in teaching. But it will also be important to go back to the literature about inclusive research, barriers and overcoming them. I also think that the next step of writing the methodology section will support my apprehension by reminding me about the process of analysis.

What I am most struck by so far, are the people I have met, both service users and the families of which they are part of. I have heard a diverse range of narratives, which I have found genuinely interesting and whose lives are certainly rich of meaning.

10/03/15

During the service user analysis I became aware of the absence of fathers (families of origin) for service users. Where participants spoke about families of origin, this included mothers, siblings or grandparents but never fathers. I feel that this is something to discuss in my next bracketing interview considering my own family history.

Appendix IV: Extract from Transcript Demonstrating Steps 1 – 3 of Data Analysis

Emergent Themes	Original Transcript	Exploratory Comments
Positive experiences of Adult Placements	K: okay, so [Service User 1], can you tell me about living here, in your adult placement. P: Yes, yes, it's very nice [.] K: It's very nice. P: Yes.	*Very short answer but answered with certainty.* Positive affirmation about living where Service User 1 is living.
Length of time in Adult Placement	K: How long have you lived here? P: 14 years. K: 14 years [.] And who lives here with you? P: [Carer 1] and Mal.	<u>Sense that this is a long time? Is it a long time for Service User 1?</u>
	K: [Carer 1] and Mal? Is that right? P: Yes, and the dog (laughs)	Adult Placement Carers
Family as represented in photographs/ paintings and displayed in family home	K: And the dog, who I met as I came in, Bronwen isn't it? P: Yes, Bronwen. K: She's lovely. P: Yes, we used to have a photograph of her up there (points to the wall). That's Mal himself (points to a painting on the wall). K: Oh, that's Mal P: Yes. K: Who did the paintings?	Names the family pet dog but laughs at his own answer – why does Service User 1 laugh? <u>Is it uncomfortable for him to recognise the important of the dog to him?</u> Service User 1 uses concrete visual representations (photograph and painting) of family members when talking about them
	P: A lady did it. She did one of Mal and the dog. K: Oh lovely. [.] Okay, so what do you like about living here? P: Oh, um, it's nice. [.] K: It's nice, what's nice about it?	Less certain than before – uses 'oh, um' and 'nice' rather than 'very nice' but different question – before – tell me about your Adult Family Placement, here – what do you like about

Getting on with the family Relationship with carers is important Opportunity to engage in activities of daily living	P: I get on with them. K: You get on with them. P: Yes.[.] K: What do you do during the week? P: Oh I do the washing up and that. And the rubbish. K: Oh you do the washing up and put the rubbish out. P: Yes.	living here. Getting on with Carers – first thing that Service User 1 says about what is nice about living here – <u>prioritises relationship over tangible/concrete things.</u> Names household activities of daily living
	K: Do you go to…where I met you first? Is it a day centre? Where you do cooking and things like that? P: (sneezes)	Opportunity to attend day service. <u>Introduces idea of difference</u> - what the day
Opportunity to go to day service	K: Oh, bless you. P: (laughs, sneezes again) K: Oh, bless you again, are you okay?	centre was before – <u>sense of change over time</u> <u>Introduces sense of movement – change in</u>
What the day centre used to be Where the day centre used to be	P: Yes, [names day service]. Used to be a fire station. K: Oh, I didn't know that. P: Before that, it used to be in [name of area]. Right up to the 60s. Then it moved up to [name of place] then. They had two fire engines or three fire engines. Where they put our clothes, coats. That's where the bay used to be. The fire engine used to sit.	<u>geographical area</u>. Concrete descriptions (e.g. clothes/coats and fire engines/bays) to <u>illustrate difference and change over time – then and now.</u> Shares historical knowledge <u>– is the history of things important to Service User 1?</u>
Comparing what is now to what is past/gone Moving Military language Structure	K: Oh that's interesting. P: The doors are gone now. The door's, they used to go up. They got one in by [name] Hospital now. K: Oh okay. P: Yes, they moved up there. The bigger one is in [name of place]. That's the head quarters. K: Oh okay. So the day centre that you go to, you used to go there when it was at [name of place]. P: [name of place]	What is now and what is past/gone. Movement – doors going up and down Things/people moving. *Introduction of term 'head quarters' – often used by military.* Sense of structure/organisation

	K: OK, what do you do on weekends?	
Opportunities to engage in ADL.	P: I go shopping with [Carer 1].	Opportunity to engage in activities of daily living
	K: You go shopping with [Carer 1], do you go food shopping, clothes shopping?	
Availability of choice/options	P: Yes, yes, to [name of supermarket]. There is two in [name of place]. One in [name of place] and one further down.	Options/choice available.
Geography and space	K: Oh okay, so you have a choice.	Sense of space/geography.
	P: Yes.	
	K: What else do you like doing on weekends?	
Opportunity to engage in leisure activities	P: Going for walks.	Opportunity to engage in activity – 'normal' life.
	K: It's a lovely place to go for walks.	
Opportunity to engage in religious activities	P: Yes, and Sundays I go to church. There's one up here, the chapel, and there's one in [name of place].	Religious beliefs – important to Service User 1?
	K: And do you go the one that's closest?	Opportunity to attend church and options/choice
Available choices/options	P: Yes, there is one [service] up here next Sunday. And the following Sunday it's down [name of place].	available to him
	K: okay, and do you know lots of people in the church who also go?	*Up here and down there* – geographical sense of
	P: oh yes.	movement.
	K: And they all know you?	
Opportunity to engage in community activities	P: Oh yes, yes.	
	K: And do you know lots of your neighbours around here?	Relationships available to Service User 1 via the
Opportunity to develop relationships with social network	P: Yes, I do, yes. Elsie's next door to us.	church – friendships? Community? Social network? How well does he know these people?
	K: Do you chat with them?	How close is he to them? *Repetition of 'yes' –*
	P: Yes, yes. I chat to Elsie. And the vicar lives down there at Number 1. He bought the bungalow, the house there. And he brought his family down. They bought Number 1, it used to be a B&B at one time. A bed and breakfast.	*emphasised how well they know him.* Neighbourhood relationships, community.

Key to types of exploratory comments (please see Method Chapter, section 2.9.3, Steps 2 and 3: Initial noting and developing emerging themes, for full description of the noting comments):

Descriptive comments

Linguistic comments

<u>Conceptual comments</u>

Appendix V: Ethics Committee Approval

CARDIFF UNIVERSITY

SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE

Committee Decision and Feedback Form

This project has been scrutinised by the School of Psychology Research Ethics Committee. The Committee's general remit is to ensure that adequate measures have been taken to avoid any ethical problems that could reasonably be anticipated on the basis of generally agreed ethical guidelines like those set out by the BPS. Approval of a research proposal means that in the Committee's opinion this proposal meets this criterion; responsibility for any breach of ethical conduct rests with the individual researcher. Should any unforeseen problems arise during the conduct of this research, the Chairman of the Ethics Committee (Dr Michael Lewis) should be informed.

Project Proposal: Karin Lewis (PG), Neil Frude, Rosemary Jenkins (Staff), Rachel Potter (Ext Clinical) - An Investigation into the Experiences of Service Users Living in Adult Family Placements and their Relationships with their Carers (EC.14.09.09.3842), supervised by Rosemary Jenkins.

The Ethics Committee considered the above proposal and noted the application had been well prepared. The following comments were made:

.1 The Committee noted that it is explained to the service user participants on P.34 (consent form 1) that the study write-up will use the information provided by them in an anonymous way - "I agree for Karin to write down what I say and put it in a report. I know that my name will not be in it". The Committee suggested that a similar statement is used on P.35 (consent form 2) so that it reads as follows: "I agree to the things _____ tells Karin to be written up in a report. My name will not be used in the report".

.2 The Committee sought clarification on the steps that will be taken by the researcher to ensure the subjects are able to participate in the conversation fully. The consent forms are very clear due to the visuals therefore the individuals may find these easy to follow.

However, when it comes to the questions the concept is not so easy to follow. It may be the case that some individuals may have to drop out of the study. The Committee recommended that the inclusion/exclusion criteria for the study could be made more clear or that the materials are made more simple. The Committee also noted that it may be the case that researchers will tailor the interviews according to the skills of the person they are talking to. Confirmation was sought.

.3 The Committee queried the relevance of the question 'What do you dislike about X?' (Page 18) and was concerned that it is inviting criticism about their carer. Could this question be removed, or replaced with 'What do you like about X?'.

.4 The Committee also queried the relevance of asking questions about people they have felt close to in the past. Such people may have caused difficulties. If participants become upset how will researchers handle this?

.5 The Committee noted that on Page 29 under 'Will I tell anyone else what you have said?' the response is 'What you tell me will be kept private'. This is not strictly true because quotations may be used. Researchers will need to get across confidentiality in a more simple way.

DECISION: Revise and resubmit proposal (to be dealt with prior to the next meeting of the Ethics Committee).

Please submit the following to Psychethics as soon as possible:

- Written response to each of the above points with details (incl. Page numbers) of any changes made to the proposal. (Please insert your response after each of the points above.)
- A copy of the amended proposal with any changes **highlighted**

NB: You may not proceed with this study until the requested revisions have been made and approved by the Ethics Committee.

Please note that it is in the researcher's interests to submit revisions to the Secretary of the Ethics Committee as soon as possible. Upon receipt, revisions will be passed immediately to the Chair of the Committee. If satisfactory, the proposal will be approved via Chair's action PRIOR to the next

meeting of the Ethics Committee. The Secretary will notify the researcher and supervisor of the Chair's decision.

Email confirmation of approval from the secretary following amendments:

Ethics Feedback - EC.14.09.09.3842R

psychethics Karin

Lewis;rosemary.jenkins2@wales.nhs.uk;rosemary.jenkins3@wales.nhs.uk;

Dear Karin,

The Chair of the Ethics Committee has considered your revised postgraduate project proposal: An Investigation into the Experiences of Service Users Living in Adult Family Placements and their Relationships with their Carers (EC.14.09.09.3842R).

The project has now been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,

Natalie

From: Karin Lewis
Sent: 16 September 2014 18:59
To: psychethics
Cc: rosemary.jenkins2@wales.nhs.uk; rosemary.jenkins3@wales.nhs.uk
Subject: C1269059 Research revisions

Hi Natalie,

Please find attached my response to the Committee's feedback and amended documents. I hope that this is satisfactory to meet the Committee's requests for amendments/clarification.

I have copied in my supervisor, Rosemary, who can confirm the response and amendments.

Please do not hesitate to contact me should you require any further information.

Kind regards,

Karin

Appendix VI: Service User Participant Information Sheet

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

<u>**Service User Participant Information Sheet**</u>

"The Experiences of Service Users Living in Adult Placements"

My name is Karin Lewis. I am training to be a Clinical Psychologist.

As part of my training I am doing a research study. In this study I am interested in talking to adults with learning disabilities who live in adult placements.

I would like you to be one of the people I talk to.

This leaflet will tell you about my study. You can talk to your family carer and social worker about this study if you want to.

Please ask questions if you do not understand anything in this leaflet.

What is research?

Research is one way we try to find the answers to questions.

Research gives people the chance to tell other people about their lives and about what they think about things.

Why is this research project being done?

I think it is really important that people with learning disabilities have a chance to tell other people about their lives and what they think about things.

This study will help to find out about the lives of people with learning disabilities.

I would like to talk to you about what it is like to live in your adult placement. I'd like to know how you feel about it.

Why have you been asked to take part?

You have been asked to take part in this study because you are living in an adult placement.

Who else will take part?

Other people who also live in adult placements will be asked to take part in the research.

I would also like to talk to carers who provide adult placements about their relationships with service users and how they support them.

Do you have to take part in the research?

You do not have to take part. It is your choice. If you do not want to talk to me then that is OK. Nothing will happen to you if you say no.

If you are not sure, you can ask your family carer, social worker and anyone else to help you to decide if you want to take part.
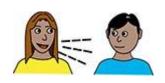
186

If you agree to meet with me and then change your mind, that is OK. You can change your mind about taking part at any time. This will not change the support that you get from anyone and it will not change anything about where you live.

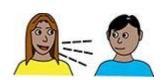**What will happen if you decide to take part?**

I will contact you to arrange a place and time to meet. I am happy to meet you at home or somewhere you feel comfortable. We will meet for about an hour.

I will talk to you about what it is like to live in an adult placement. I would also like to talk to you about your adult placement carer and other people who are important to you.
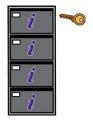
I will ask you what is good about where you live and the people you live with and what is hard about it – if you do not want to answer any of the questions then that is OK.
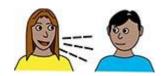
I would also like to talk to your adult placement carer about how they support you. I will ask you if you are happy for me to talk to your carer – you can say 'yes' or 'no'. Nothing will happen to you if you say 'no'.

I will record what you tell me and write this up. I will not use your name when I write it up so only I will know who said those things. The tape will be wiped at the end of the study.

The recording and the write up will be kept in a locked drawer in my office in the University.

187

I may ask to meet you again, to check that I have understood what you told me.

What will I do with what you tell me?

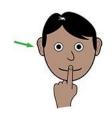I will put what you tell me together with what other people who live in adult placements tell me. I will write it up in a report.
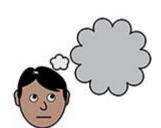
Will anyone else know what you have said?

Everything you tell me will be confidential – this means that I will not tell anyone else what you say to me. Some parts of the report will have quotes about what you said but your name will not be in it.

If you tell me something that makes me worried about your safety then I will have to tell someone about this. For example, if you think that you may harm yourself or someone else then I will need to tell other people who are supporting you. I will tell you if I need to do this.

Will taking part help you?

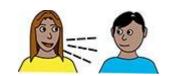I hope that you will enjoy talking to me. It might feel good to talk about what it is like to live in your adult placement. Talking to me will not change your adult placement or the support that you get.

I cannot promise that taking part in the study will help you but the results of the research may help others to understand the support needs of people with disabilities and improve support for others in the future.

What if any of the questions upset you?

You can decide what you would like to talk about. If you get upset, we can stop the interview. I will help you and support you. We can take a break or stop altogether. If you do not want to answer a question then that is OK.
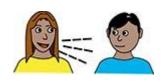
If you would like to talk to your adult placement carer or social worker because you are upset then that is OK.

What will happen to the results of the research?
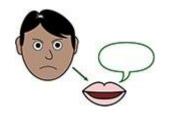
I will write the results up into a report. This is because it is part of my training to become a Psychologist. The report will be read by other Psychologists.

I might then write about it in a magazine called a 'journal'. Your name will not be in it. I may also talk about the research to others. I will tell you about what I have found out if you want me to.

What can you do if you are unhappy about anything in the research?

If you feel upset or unhappy about something during the study, please talk to me and I will try to help. You can also talk to my supervisors, Rosemary Jenkins or Rachel Potter, who may also help. Their phone numbers are at the end of this leaflet.

If you are unhappy about anything I have said then you can make a complaint.

Who has agreed that this study is safe?

All research is looked at by a group of people called a Research Ethics Committee. The School of Psychology Research Ethics Committee have agreed that this research is safe.

How do you take part?

If you are interested in taking part in the research, please complete the consent form and give it to the person who went through this leaflet with you. You can ask them to help you with this. That person will contact me and send me the consent form.

Once I get the consent form, I will phone you to arrange to meet. If you do not want to take part in the study, do not complete the consent form and I will not contact you.

What if you have more questions?

If you would like to find out more about my study, you can get in touch with me or my supervisors, Dr Rosemary Jenkins (Consultant Clinical Psychologist, ▓▓▓▓▓) or Dr Rachel Potter (Clinical Psychologist, ▓▓▓▓▓). Our phone numbers are at the end of this leaflet.

Contact Details

You may contact me at any time after we meet if you are worried about something to do with the study, or to ask any questions that you have about the study.

Karin Lewis
Trainee Clinical Psychologist

School of Psychology
11th Floor
Tower Building
School of Psychology
70 Park Place
Cardiff
CF10 3AT

Tel: 02920 870582
Email: Karin.lewis@wales.nhs.uk

You can also contact my supervisors if you do not want to speak with me.

Dr Rosemary Jenkins (   )   Dr Rachel Potter (   )
Consultant Clinical Psychologist   Clinical Psychologist

School of Psychology
11th Floor
Tower Building
School of Psychology
70 Park Place
Cardiff
CF10 3AT

Tel: 02920 870582   Tel:
Email: Rosemary.Jenkins3@wales.nhs.uk   Email: Rachel.Potter3@wales.nhs.uk

Appendix VII: Adult Placement Carer Information Sheet

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Adult Placement Carer/Provider Information Sheet

An Investigation into the Experiences of Service Users Living in Adult Placements and their Relationships with their Carers

You are invited to take part in a new study investigating the relationships that develop over time between service users with a learning disability and their adult placement carers.

I would like to hear your experiences of supporting a person with a learning disability, paying particular attention to how you understand the nature and meaning of your relationship in supporting that individual.

Who is asking you to take part?

My name is Karin Lewis and I am a Trainee Clinical Psychologist on the South Wales Doctoral Programme in Clinical Psychology. I am doing this research project as part of my studies in order to qualify as a clinical psychologist.

This information sheet is intended to tell you about the interview that I will be doing with the person who you support and to invite you to also take part in an interview.

What is the purpose of this study?

The purpose of this study is to explore the experiences of adults with a Learning Disability living in Adult Placements. The participants will be asked what it is like to live in an Adult Placement and to think about their relationships with the members of the family that they live with.

Adult Placements provide a unique form of care and previous research has explored the experiences of the people who provide such placements. This has highlighted

some of the benefits and challenges from the perspective of the providers. Further research is needed to explore the experiences of the adults with a learning disability who live in such placements and the relationships between service users and carers/providers. Little is known about the experience of Adult Placements from a service user's perspective.

It is hoped that the findings of this study will inform practice in relation to:

- supporting the needs of people with learning disabilities
- contributing to and highlighting implications for clinical practice and service provision
- providing a better understanding of the relationships developed by people with learning disabilities
- promoting a person centred approach, and
- empowering people with learning disabilities

What will the study involve?

I would like to interview 5-6 people with a learning disability and 5-6 adult placement carers/providers. My plan is to interview the service user first about their experiences of their adult placement and the important relationships in their lives. As part of this process, I will ask their permission to also interview their adult placement carer/provider who they have known for at least six months. I would like to find out from service users what they value most about their relationship with their carer and the type of support they receive, particularly at times of difficulty or distress. I will then ask the service user's consent to interview their carer (you) about their perspective of the relationship.

Please note that the study is in no way an evaluation of individual adult placement carers/providers or service users. Rather, it aims to develop an understanding of the relationships between service users and carers/providers and their role in meeting the emotional needs of people with learning disabilities. The questions that I will ask the service user are worded a little differently to the carer interview, but both interviews are aimed to explore similar issues. The date, time and venue of the interview can be arranged at the participant's convenience. Each interview will take around an hour and I will only need to interview participants on one occasion.

What is expected of you?

In the first instance, I am asking for your consent for me to interview the service user who you support (the service user will also be asked to consent to their own participation in the research). The reason why you are also being asked to consent to the service user interview is that the participant may talk about your family life and

the relationships they have developed with you and other family members. All family members supporting the participants can be provided with this information sheet.

Secondly, you will be approached to take part in an interview about your experiences of supporting a person with a learning disability, paying particular attention to how you understand the nature and meaning of your relationship in supporting that person. I will contact you by telephone to find out if you would like to meet me for an interview and I will answer any questions that you have about the interview process or the study in general.

Do you have to take part?

There is no obligation for you to agree to the person in your care taking part or to taking part yourself and you are free to decline. If you do agree to take part, you will be asked to sign a consent form to show that you have agreed to one or both of these interviews taking place. However, you are free to change your mind at any time and pull out of the project, without giving a reason. This will not affect you in any way.

Will the information gained be kept confidential?

Yes. The researcher follows a strict ethical and professional code of conduct that requires that all information must remain confidential and anonymous. The researcher will audio-record the interviews and transcribe the data. Each of the audio-recordings will be given a code and stored safely to maintain anonymity. Participants' names and the names of all family members talked about will be changed during the transcribing and in the write up of the study so that they will not be identifiable. The recordings and the transcripts will be stored in a locked cabinet within the University, and only the researchers in the study will have access to the data. The audio-recording will be destroyed following its transcription.

In accordance with policy, confidentiality will only be broken if the researcher becomes aware of risk to the participant or another person. The researcher will inform the participant if confidentiality needs to be broken. If this occurs, the researcher will discuss this information with Dr Rosemary Jenkins. The researcher will inform the participant about what they will do next.

What are the possible advantages of the study?

This is your opportunity to express your views about important aspects of your role and to share your knowledge and expertise about supporting people with learning

disabilities, in particular about their emotional needs. It is hoped that the study will contribute to the improvement of services for people with learning disabilities.

What are the possible disadvantages of the study?

There are no known risks involved in taking part in this study. Although the topic under consideration in not especially sensitive, the interview is designed to be exploratory and, depending on the themes that emerge, it is always possible that the interview might raise personal issues. If at any stage you find the topic difficult to talk about, become distressed or wish to discontinue for any reason then I will stop the interview immediately and provide support. There will be no obligation for you to continue with the interview and you can decide to postpone the interview until a later date or to withdraw from the study altogether. It is also possible for the researcher to arrange for participants to speak with someone independent of the research, for example an Adult placement officer.

What will happen to the findings of the study?

The findings of this study will be written up as part of the researcher's doctoral thesis, which forms part of their Doctorate in Clinical Psychology. It will be submitted and assessed by an examination panel. As part of the write-up the researcher will use quotes from the interviews, but all information will be anonymous. A summary sheet of the findings will be provided to those participants who request it.

It is also hoped that the findings from the research will be published in an academic journal and presented throughout the NHS, local authority and third sector organisations in Wales and England.

What if there is a problem?

If you are concerned about any aspect of the study, you can speak to me at any point and I will do my best to answer your questions. If you remain unhappy and wish to make a complaint then I can inform you of the contact details of the people who may be able to respond to your concerns.

Who has agreed that this study is safe?

All research undertaken within Cardiff University is carefully monitored by a Research Ethics Committee. This committee ensures the safety and rights of all

participants in the study. This study has been reviewed and approved by The School of Psychology Research Ethics Committee.

Further information

If you would like to find out more about the study, you can contact me (Karin Lewis) or my supervisors, Dr Rosemary Jenkins (Consultant Clinical Psychologist, ███████) or Dr Rachel Potter (Clinical Psychologist, █████████) or Professor Neil Frude (Research Director). The details are below.

THANK YOU FOR TAKING THE TIME AND READING THIS INFORMATION SHEET

Contact Details

Karin Lewis
Trainee Clinical Psychologist

School of Psychology
11th Floor
Tower Building
School of Psychology
70 Park Place
Cardiff
CF10 3AT

Tel: 02920 870582
Email: Karin.lewis@wales.nhs.uk

You can also contact my supervisors, Rosemary Jenkins, Rachel Potter or Neil Frude, if you do not want to speak with me.

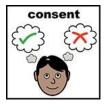| Dr Rosemary Jenkins Consultant Clinical Psychologist (███████)	Dr Rachel Potter Clinical Psychologist (███████)	Professor Neil Frude Research Director
School of Psychology 11th Floor Tower Building School of Psychology 70 Park Place Cardiff CF10 3AT	████████████	School of Psychology 11th Floor Tower Building School of Psychology 70 Park Place Cardiff CF10 3AT
Tel: 02920 870545 Rosemary.Jenkins3@wales.nhs.uk	Tel:█████████ Rachel.Potter3@wales.nhs.uk	Tel: 02920 870545 Neil.Frude@wales.nhs.uk

Appendix VIII: Service User Participant Consent Form 1

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Service User Participant Consent Form(1)

"The Experiences of Service Users Living in Adult Placements"

Researcher: Karin Lewis, Trainee Clinical Psychologist

If you agree with the statement please put your initials in the box

1. I have read (or had read to me) the information sheet about the study dated 15.09.14. I understand what I have read and what I have been told about the study.

2. I have had chance to ask any questions that I had.

3. I know that I can say 'no' to the research if I don't want to do it. I know that I can stop doing the study at any time. I know this will not change the support that I get in any way.
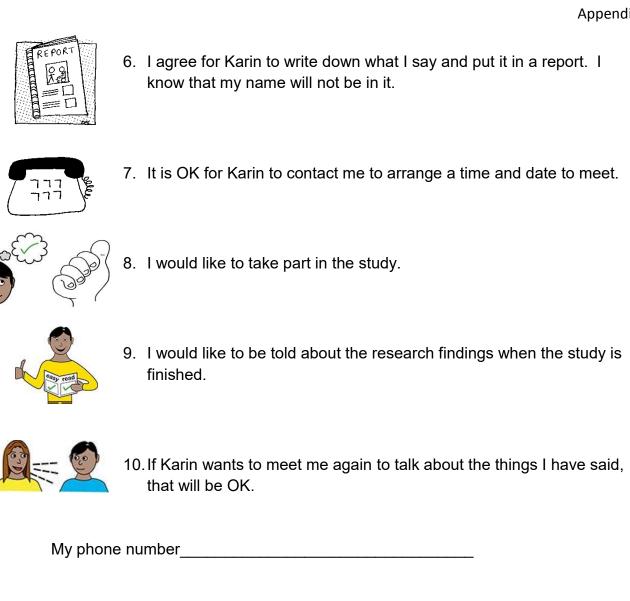
4. I agree to the interview being recorded so that Karin can listen to it again and write down the things I said.

5. I understand that everything I say will be kept private (confidential) unless Karin is worried about someone's safety.

6. I agree for Karin to write down what I say and put it in a report. I know that my name will not be in it.

7. It is OK for Karin to contact me to arrange a time and date to meet.

8. I would like to take part in the study.

9. I would like to be told about the research findings when the study is finished.

10. If Karin wants to meet me again to talk about the things I have said, that will be OK.

My phone number_____

Name: ……………………………Signature: …………………………………………

Date: …………………………………

I, the undersigned, confirm that I read through and discussed the information sheet with the participant who has agreed to take part in the study:

Person taking consent (print): ……………………………………………………………

Signature: …………………………………………………..

Date: ……………………………………………….

Appendix IX: Service User Participant Consent Form 2

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Service User Participant Consent Form(2)

"The Experiences of Service Users Living in Adult Placements"

Researcher: Karin Lewis, Trainee Clinical Psychologist

If you agree with the statement please put your initials in the box

1. It is OK for Karin to phone _____ (adult placement carer) for an interview.

2. I am happy for Karin to ask _____ questions about how he/she supports me.

3. I agree to the things _____ tells Karin to be written up in a report. My name will not be used in the report.

I agree to the above.

Name: ……………………………….

Signature: ……………………………………….

Date: …………………………………

Researcher's Name: ………………………………………………………

Signature: ………………………………………………..

Date: ………………………………………………

Appendix X: Carer Participant Consent Form 1

South Wales Doctoral Programme In Clinical Psychology
Cwrs Doctoriaeth De Cymru mewn Seicoleg Clinigol

<u>Adult Placement Carer/Provider Consent Form(1)</u>

An Investigation into the Experiences of Service Users Living in Adult Placements and their Relationships with their Carers

Consent for the Service User Interview

Researcher: Karin Lewis, Trainee Clinical Psychologist

If you agree with the statement please put your initials in the box

1. I have received and read the information sheet about the study.

2. I give my consent to the interview with _____(service user) taking place. I understand that my consent is being requested due to the possibility of my home and family life being discussed within the interview and that all information will remain confidential and anonymous.

Name: ………………………………….

Signature: ……………………………………….

Date: …………………………………

I, the undersigned, confirm that I read through and discussed the information sheet with the adult family placement carer/provider who has agreed to the service user interview being undertaken:

Person taking consent (print): …………………………………………………

Signature: ………………………………………..

Date: ………………………………………….

Appendix XI: Carer Participant Consent Form 2

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

<u>Adult Placement Carer/Provider Consent Form(2)</u>

An Investigation into the Experiences of Service Users Living in Adult Placements and their Relationships with their Carers

Consent for the Carer/ Provider Interview

Researcher: Karin Lewis, Trainee Clinical Psychologist

If you decide to take part in this study, all of the information provided will remain strictly confidential. You are under no obligation to take part in the study and would have the right to withdraw at any time.

If you agree with the statement please put your initials in the box

1. I have received and read the information sheet about the study.

2. I agree to take part in a tape recorded interview with the researcher.

3. I consent to the information that I provide being included in an academic report to be written by the researcher and submitted as part of a doctoral qualification and other reports that might be written from this.

I agree to take part in this study.

Name: ……………………………….

Signature: ……………………………………….

Date: ………………………………

Researcher's Name: ……………………………………………………

Signature: ………………………………………………..

Date: ………………………………………………

Appendix XII: Accessible Information Sheet for TRAC Meeting
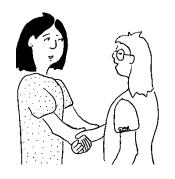

Information sheet

My name is Karin

I am an Trainee Clinical Psychologist

I am doing a research project. I will be talking to people with a learning disability who live in Adult Family Placements.

Adult Family Placements are provided by people in the local community, who share their home and their lives with people who need support to live more independent lives.

I would like to know what people think about living in adult family placements.

- What is good about it
- What is difficult about it
- If there is anything they would change about where they live.

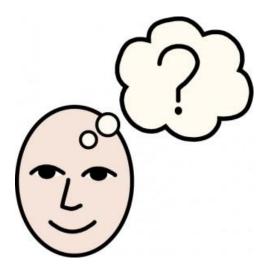I also want to know about their relationships with the families that they live with.

I want to know how they came to live in adult family placements:

- Were they given a choice?
- Were they included in the decisions about where they live

Today, I'd like to know what you think about my research project. And if you have any advice for me about it or about doing research with people with learning disabilities.

Appendix XIII: Service User Semi-Structured Interview Schedule

Semi-Structured Interview Schedule

The following questions will provide a framework for the interview, with visual prompts used to help service users generate responses where appropriate.

Part 1: Rapport building and relationship circle exercise

1. Introduction
- Go through information leaflet to check understanding
- Reaffirm consent
- Elicit worries/questions
- Ask for permission to take notes in addition to taping

Prompts:
- *Thank you for meeting with me today.*
- *I would like us to read through the information sheet together first of all, just to remind you what my study is about.*
- *I will ask you some questions to learn a bit about you.*
- *There are no right or wrong answers to the questions.*
- *I will ask you about the important people in your life. I have an exercise to help us think about this.*
- *I will ask about your family placement carer and how they support you.*
- *I will ask you about your adult placement and how you came to live here*
- *Any worries or questions before we start?*

2. Warm-up Questions/ Background Information
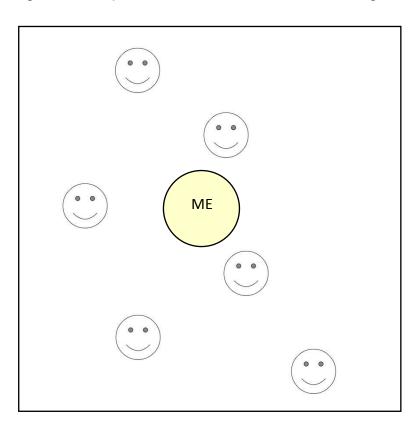*Tell me about living here/in your adult placement*

Prompts:

- How long have you lived here?
- Who lives here with you?
- What do you like about living here?
- What do you enjoy doing?
- What do you do during the week?
- What do you do on weekends?

3. Relationship Circle Exercise

Rationale: to provide a broader relationship context and to ascertain who the service user identifies as feeling close to.

The participant will be asked to draw a picture of him/herself or write their name in a circle positioned in the middle of a large piece of paper. They will be asked to make a list of all the important people in their life that they feel close to e.g. family, friends, adult placement carers. The participant will then be asked to position each person around their own circle (can draw or just write their name) according to how close they feel to them, so that individuals they feel closest to are the nearest to their circle and those they feel less close to are furthest away. The resulting relationship circle should resemble the following:

Part 2: Core Themes and Prompts for Discussion

I'm going to ask about your adult placement later but first I'd like to talk to you about the important people in your life, your family placement carer and how they support you. You views are very important and will be very useful.

1. The Important People in Your Life
   Can you tell me about the people in the circle?
   Prompts:
   - How long have you known…?
   - Who do you spend most time with?

- How do you spend time with…?
- What about your family placement carer? Who do you feel closest to/spend a lot of time with?
- What kind of support do they give you?

2. Relationship with X (family placement carer)
   Can you tell me about your relationship with X (family placement carer)?

   Prompts:
   - How do you get on with X?
     - Has it always been like that?
     - How has it changed?
   - What do you like about X?
   - Is there anything you do not like about X?
   - How do you like to spend time with X?
   - What was it like getting to know X?
   - Are there any ways you would like it to be different?

3. People you have felt close to in the past
   What about people you have felt close to in the past? Can you tell me about them?
   Prompts:
   - Do you still see them/speak to them?
   - How do/did you get on with them?
   - How do/did you spend time with them?
   - What do/did you like about them?
   - What is/was special about them?
   - Where would you put them in the exercise?
   - How are they like X (family placement carer)?
   - How are they different?

4. Relationships with other family members within your placement
   Can you tell me about the other family members within your adult placement?

   Prompts:
   - Who else in your adult placement do you see and spend time with?
   - How do you get on with them?
     - Has it always been like that?
     - How has it changed?
   - What do you like about them?

- Is there anything you do not like about them?
- How do you like to spend time with them?
- What was it like getting to know them?
- Are there any ways you would like it to be different?

5. <u>How X (family placement carer) helps you</u>
OK, let's think again about your adult placement carer again, tell me about how X helps you

Prompts:
- What does X help you with?
    - How do you feel about how X helps you with that?
    - What do you think about how X helps you with that?
- Does X help you when you are upset or worried? (use emotions cards)
- What sorts of things make you upset/worried?
    - How does X help you then?
    - What do they do?
    - How do you feel about it?
    - What do you think about it?
- Ask for a concrete example to discuss e.g. can you remember the last time you felt upset?
    - What did X say/do to help?
    - How do you feel about it?
    - What do you think about it?
- What else does X help you with?

6. <u>Times without X</u>
Can you tell me about times without X?

Prompts:
- Are there times when you go and stay somewhere else?
    - Who do you stay with?
    - Do you go to respite?
        - What is good about it?
        - What is hard or difficult about it?
        - What would you like to change about it?
        - How do you feel about it?
        - How is it different to your adult placement?
    - What is it like without X?
        - How do you feel about it?
        - What do you think about it?

- o Who do you spend time with when you are not with X?
- o Does [other person] help you the same way as X?
  - How do you feel about it?
  - What do you think about it?
- Are there times when X is not here?
  - o Who do you like to spend time with when X is not here?
  - o Does [other person] help you the same way as X?
    - How do you feel about it?
    - What do you think about it?

7. <u>Living in an Adult placement</u>
I'd now like to talk to you about your family placement and how you came to live here.

What is it like living in an adult placement?

Prompts:
- What is good about living here/in an adult placement?
- What is the best thing about living here/in an adult placement?
- What is hard or difficult about living here/in an adult placement?
- Is there anything that you would change about living here/in an adult placement?
- If one of your friends was going to live in an adult placement, what would you tell them it was like?
- Where did you live before?
- How is living here different?
- How is living here the same?

8. <u>How you came to be living in the adult placement</u>
Can you tell me how you came to be living here?

Prompts:
- Did you have a choice in deciding where you want to live?
- Did you choose to live here or did someone else tell you that you would be coming to live here?
- Is living here what you wanted?
- Did you meet your carer before coming to live here?
  - o Did this help you decide what you wanted?

9. <u>Finishing off</u>
   Is there anything else you would like to say about your adult placement or about X?

   Prompts:
   - Is there anything you would like to ask me?
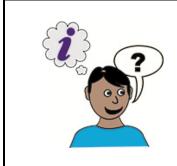
10. <u>Closing</u>
    Prompts:
    - That's all I wanted to ask.
      - How has it felt to talk to me?
      - Has it raised any issues/ feelings/ thoughts that you were not aware of or want to discuss with me?
    - Thank you for your time helping me.
      - What are you going to do next? Later? For the rest of the day?
      - Have you any plans that you are looking forwards to?

Appendix XIV: Examples of Images to Supplement Interview Schedule

Part 1: Rapport Building and Relationship Circle Exercise

ask you what you think	**I would like to ask you some questions**

	Any worries or questions before we start?

live with a family	**Living in an Adult Placement**

NB. See Interview Schedule for example of relationship circle exercise (visual image to be drawn out with participant).

Part 2: Visual images to be used alongside relationship circle
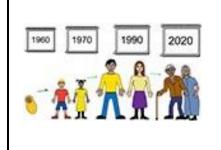
	The Important People in Your Life
	Relationship with Carer
	Like/Don't like
	People you have felt close to in the past
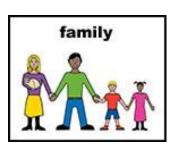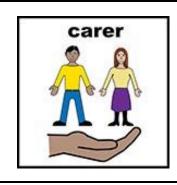
family	Relationships with other family members within your placement

carer	help	How does your carer help you

how do you feel	How do you feel about it?

	What do you think about it?

upset	**Upset/Worried**
	Respite/Times without Carer
live with a family	**Living in an Adult Placement**
	Good/Bad
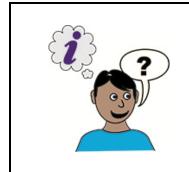
	Choice of where to live

	Anything else you would like to say

	Any questions?

Appendix XV: Adult Placement Carer Semi-Structured Interview Schedule

Semi-structured Interview Schedule

(Adult Placement Carers)

As outlined in the information sheet, I am doing a research project around the experiences of adults with a Learning Disability living in adult placements and I am particularly interested in the relationships they have with the family members they live with and other people in their lives. I would therefore be really keen to hear about the relationship you have with X (service user) and your understanding of his/her emotional needs.

CORE THEMES AND PROMPTS FOR DISCUSSION

1. Warm-up Questions/Background Information

   Tell me about how you first heard about the adult placement scheme?

   Prompts:
   - How long have you been involved with the adult placement scheme?
   - How do you perceive your role as an adult placement carer/provider?
   - How is this role similar or different to other caring roles, e.g. as a mother, father, friend, support worker?
   - Can you tell me about your relationship with the adult placement team?

2. Providing an Adult placement for X

   Can you tell me about your experiences of having X living here?

   Prompts:
   - How do you think X has settled in?
   - How do you think X fits in with the family?
   - What do you think are the benefits for X?
   - What do you think are the challenges/dilemmas for X?
   - What are the benefits of having X living here for you and the family?
   - What are the challenges of having X living here for you and the family?

2. The Important People in X's life

Who would you say are the important people in X's life?

Prompts:
- Who do they spend most time with?
- How do you spend time with X?
- Who do you think X is closest to?

3. Your Relationship with X

Can you tell me about your relationship with X?

Prompts:
- What do you think are the positives about your relationship with X?
- What do you think are the challenges about your relationship with X?
- What was it like for you getting to know X?
- What do you think it was like for X getting to know you?
- Are there any ways you would like your relationship to be different?
- Are there any ways you think X would like your relationship to be different?

4. X's relationships with other family members within the placement

Can you tell me about the other family members within the adult placement and their relationships with X?

Prompts:
- Who else in the adult placement does X have a relationship with?
- What do you think are the positives about the relationships for X?
- What do you think are the challenges about the relationships with X?
- What was it like for other family members getting to know X?
- What do you think it was like for X getting to know other family members?
- Are there any ways you think X would like the relationships to be different?
- Having X live here, how has that changed how you are as a family?

5. X's current support needs

OK, back to your relationship with X, what is your understanding of X's current support needs?

How would you describe your role/responsibilities in supporting X with the above needs?

Prompts:
- How do you support X with practical, emotional and psychological support needs?
- How do you help X when they are upset or worried?
- How do you think X feels/thinks about how you support him/her?

6. Times when you are not with X

Can you tell me about what it is like at times when X is not here?

Prompts:
- What are the positives about times when X is not here?
- What are the challenges about times when X is not here?
- How do you think X feels/thinks about times when he/she is not here?

7. Your support needs
How would you describe your own support needs regarding the relationship with X?

8. Final Reflections
Are there any other thoughts or comments that you think might be important for this study and would like to add?

Appendix XVI: Service User De-Briefing Form

Service User Participant De-briefing Form

"The Experiences of Service Users Living in Adult Family Placements"

Thank you for taking part in this study.

.

I will put what you have told me together with what other people who live in adult family placements tell me.

We hope this study will help us to find out about the lives of people with learning disabilities and their relationships with other people.

If the interview has upset you, please contact us so we can help you to get some extra support. Or please let your adult family placement carer or social worker know.

The consent form that you signed will be kept in a locked filing cabinet in the Clinical Psychology Department at Cardiff University.

The tape of the interview will be written up and then wiped. Your name will not be used in the write up.

You can change your mind about wanting to take part up until the interview is written up. After this, all names will have been changed.

If you want me to tell you about the research findings when the study is finished please let me know.

If you have any questions please contact us:

Contact Details

Researcher:

Karin Lewis
Trainee Clinical Psychologist

School of Psychology
11th Floor
Tower Building
School of Psychology
70 Park Place
Cardiff
CF10 3AT

Tel: 02920 870582
Email: Karin.lewis@wales.nhs.uk

You can also contact my supervisors if you do not want to speak with me.

Dr Rosemary Jenkins (███████)
Consultant Clinical Psychologist

School of Psychology
11th Floor
Tower Building
School of Psychology
70 Park Place
Cardiff
CF10 3AT

Tel: 02920 870582
Email: Rosemary.Jenkins3@wales.nhs.uk

Dr Rachel Potter (███████)
Clinical Psychologist

Tel: ███████████
Email: Rachel.Potter3@wales.nhs.uk

If you have any questions or complaints about the research you can contact the
School of Psychology Research Ethics Committee in writing at:
Secretary to the Research Ethics Committee
School of Psychology, Tower Building,
70 Park Place, Cardiff, CF10 3AT

psychethics@cardiff.ac.uk

Appendix XVII: Adult Placement Carer De-Briefing Form

<u>Adult Family Placement Carer/Provider De-briefing Form</u>

An Investigation into the Experiences of Service Users Living in Adult Family Placements and their Relationships with their Carers

Thank you for taking part in this study. The information you have provided in your interview will be put together and analysed with the other interviews collected for this research. We hope that the results of this study will help us to understand the experiences of services users living in adult family placements and their relationships with their carers. This information could be useful for informing practice in relation to the support needs of people with learning disabilities. The study results may also provide information for clinical practice and service provision.

If the interview has caused you distress, please contact us so that we may explore avenues for you to gain extra support.

The consent form that you signed will be kept in a locked filing cabinet in the Clinical Psychology Department at Cardiff University, only accessible by the researchers. The audio recording will be transcribed and then destroyed. Your general information sheet and typed up interview will be kept anonymously. You can withdraw from participation up until the interview is typed up, because it will then contain made up names.

If you wish to have information about the results of the study please let Karin Lewis know and she will send you a summary of the results as soon as they are available.

If you have any further questions please contact us:

Researcher:

Karin Lewis
Trainee Clinical Psychologist

School of Psychology
11th Floor, Tower Building
70 Park Place, Cardiff, CF10 3AT

Tel: 02920 870582
Email: Karin.lewis@wales.nhs.uk

Clinical Supervisor (▮▮▮▮):	**Clinical Supervisor (▮▮▮▮):**	**Academic Supervisor:**
Dr Rosemary Jenkins	Dr Rachel Potter	Professor Neil Frude
Consultant Clinical Psychologist	Clinical Psychologist	Research Director
School of Psychology		School of Psychology
11th Floor, Tower Building		11th Floor, Tower Building
70 Park Place, Cardiff,		70 Park Place, Cardiff
CF10 3AT		CF10 3AT
Tel: 02920 870545	Tel: ▮▮▮▮	Tel: 02920 870545
Rosemary.Jenkins3@wales.nhs.uk	Rachel.Potter3@wales.nhs.uk	Neil.Frude@wales.nhs.uk

If you have any concerns or complaints about the research you can contact the
School of Psychology Research Ethics Committee in writing at:
Secretary to the Research Ethics Committee
School of Psychology, Tower Building,
70 Park Place, Cardiff, CF10 3AT

psychethics@cardiff.ac.uk

Appendix XVIII: Gatekeeper Letter 1

Community Support Team
Tîm Cynnal Cymunedol

18th August 2014

To Whom It May Concern:

Re: Research by Karin Lewis

This is to confirm that the ⬛⬛⬛⬛ Adult Placement Scheme is aware of the research proposal; An Investigation into the Experiences of Service Users Living in Adult Family Placements and their Relationships with their Carers, which is to be led by Karin Lewis as part of her Doctoral training requirements. I have been in contact with Karin about the study and with her Clinical Supervisor, Dr Rosemary Jenkins. As such, I consent to the access of participants via the Adult Family Placement Social Workers within our Adult Placement Scheme.
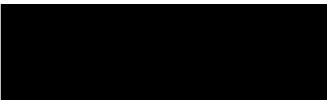
If you require any further information please do not hesitate to contact me on the number above.

Yours sincerely

Registered Manager

Appendix XIX: Gatekeeper Letter 2

18th August 2014

To Whom It May Concern:

Re: Research by Karin Lewis

This is to confirm that the ▮▮▮▮▮▮▮▮ Adult Placement Scheme Shared Lives is aware of the research proposal; An Investigation into the Experiences of Service Users Living in Adult Family Placements and their Relationships with their Carers, which is to be led by Karin Lewis as part of her Doctoral training requirements. I have been in contact with Karin about the study and with her Clinical Supervisor, Dr Rachel Potter. As such, I consent to the access of participants via the Adult Placement Scheme Workers within our Scheme.

If you require any further information please do not hesitate to contact me on the number above.

Yours sincerely

▮▮▮▮▮▮▮▮

Development Manager
▮▮▮▮▮▮▮▮ Adult Placement Scheme Shared Lives

Appendix XX: Risk Assessment for Interviews at Participants' Homes

Risk Assessment Form

IMPORTANT: Beforecarrying out the assessment, please read the Guidance Notes

1.General Information

Department	South Wales Doctoral Programme in Clinical Psychology	Building	11th Floor, Psychology Tower	Room No	N/A
Name of Assessor	Karin Lewis	**Date of Original Assessment**	22/08/2014	**Assessment No**	488_c1269059

Status of Assessor:Supervisor☐, Postgraduate☒, Undergraduate ☐, Technician ☐, Other: ....
(Specify)

2. Brief Description of Procedure/Activity including its Location and Duration

Semi-structured interview conducted with service user with a learning disability or carer who live in/provide adult family placements. Interview will be held at participant's home. Interview will last for approximately an hour and will be audio-taped. Participants will be asked about their general experiences of living in/providing adult family placements, the benefits and challenges to the placements and service user and carer relationships.

3. Persons at Risk Are they...   Notes

| Staff☐ Students ☒ Visitor ☐ Contractor☐ | Trained☒ Competent☒ Inexperienced☐ Disabled☐ | The interviews will be conducted by a trainee clinical psychologist who is employed by Cardiff and Vale UHB. It is hoped that participants will not find the interview distressing. The interview will be stopped and the participant asked if they would like to continue with the interview if they become distressed and support will be offered. The trainee is experienced in communicating with people with learning disabilities and has been trained in communicating with people in distress. The trainee will follow Cardiff and Vale UHB lone working policies when visiting participants' homes. |

4. Level of Supervision Notes

None☐ Constant☐ Periodic☒ Training Required ☐	The research is being supervised by Dr Rosemary Jenkins (Consultant Clinical Psychologist, Clinical Supervisor), Dr Rachel Potter (Clinical Psychologist, Clinical Supervisor) and Professor Neil Frude (Research Director, Academic Supervisor). The interviewer will discuss any concerns with them.

5. Will Protective Equipment Be Used? Please give *specific* details of PPE

Head ☐Eye☐Ear☐ Body ☐Hand ☐Foot☐	None

6. Is the Environment at Risk?   Notes

Yes ☐No☒	

7. Will Waste be generated?   If 'yes' please give details of disposal

Yes ☐ No ☒	

8. Hazards involved

Work Activity / Item of Equipment / Procedure / Physical Location	Hazard	Control Measures and Consequence of Failure	Likelihood (0 to 5) ✗	Severity (0 to 5) =	Level of Risk
Interviewing at participant's home	Personal Violence	Cardiff and Vale UHB lone working policy will be implemented, including: • Informing my supervisor(s) of the address I am visiting and the estimated time at which the visit will end. If neither supervisor is available then another member of staff on the DClinPsy course will be informed • I will make sure my mobile phone is fully charged before a home visit • I will ask who is likely to be at home at the time of the home visit and also request that any dogs be kept in the garden	1	5	5

		• If I do not contact my supervisor(s) before the time I have provided them with, they will contact me to ensure my safety. If they cannot contact me they will start an escalation procedure, beginning with my line manager and ultimately ending in phoning the police if I have still not been able to be contacted • I will park my car in the direction from which I will be leaving to ensure a quick exit if needed • I will make sure I shut the front door of the house to ensure it is not locked if I need to exit quickly • I will conduct the interview so that I am in a position close to an exit for safety reasons • In the face of direct threat, I will ring 999 and/or use breakaway techniques I have learnt through participation in Cardiff and Vale UHB Violence and Aggression training It is felt that the likelihood of personal attack is low. However, if control measures failed, the consequences of failure would include possible serious injury			
Travelling to and from interview locations	Road Traffic Accident or personal violence	Safe driving and business car insurance. Parking in a well lit area close to the location	1	5	5

9. Chemical Safety (COSHH Assessment)

Hazard	Control Measures	Likelihood (0 to 5) $\times$	Severity (0 to 5) $=$	Level of Risk

---

Scoring Criteria for Likelihood (chance of the hazard causing a problem)
0 – Zero to extremelyunlikely, 1 – Very Unlikely, 2 – Unlikely, 3 – Likely, 4 – Very Likely, 5 – Almost certain to happen

Scoring Criteria for Severity of injury (or illness) resulting from the hazard

0 – No injury, 1 – First Aid is adequate, 2 – Minor injury, 3 – "Three day" injury, 4 – Major injury, 5 – Fatality or disabling injury

10. Source(s) of information used to complete the above

Guidance notes for Risk Assessment form Cardiff and Vale UHB lone working policy (http://www.cardiffandvaleuhb.wales.nhs.uk/opendoc/169662)

11. Further Action

Highest Level of Risk Score	Action to be taken
0 to 5☒	No further action needed
6 to 11☐	Appropriate additional control measures should be implemented
12 to 25☐	Additional control measures **MUST** be implemented. Work **MUST NOT** commence until such measures are in place. If work has already started it must **STOP** until adequate control measures are in place.

12. Additional Control Measures – Likelihood and Severity are the values with the additional controls in place

Work Activity / Item of Equipment / Procedure / Physical Location	Hazard and Existing Control Measures	Additional Controls needed to Reduce Risk	Likelihood (0 to 5)	Severity (0 to 5)	Level of Risk

After the implementation of new control measures the procedure/activity should be re-assessed to ensure that the level of risk has been reduced as required.

13. Action in the Event of an Accident or Emergency

Use breakaway techniques if personal violence occurs. Speed dial numbers for 999 and supervisor contact to be carried on mobile phone for use in any emergency. Supervisor to phone researcher at end of session and if no response is obtained then emergency services will be called.

14. Arrangements for Monitoring the Effectiveness of Control

Ad-hoc visual checks and supervisor to be consulted in the event of any problems. No further testing to be carried out until the problem has been resolved.

15. Review: This assessment must be reviewed by (date):

Name of Reviewer:		Date of Review:	
Have the Control measures been effective in controlling the risk?			
Have there been any changes in the procedure or in information available which affect the estimated level of risk?			
What changes to the Control Measures are required?			

16. Signatures for printed copies:

Form completed by: Karin Lewis, Trainee Clinical Psychologist	Date:22/08/2014
Approved by:	Date:
Assessor:	Date:
Reviewed by:	Date:
This copy issued to: (print name and sign)	Date:

Appendix XXI: Example of Summary Table Demonstrating Step 4 of Data Analysis – Subordinate and Emergent themes

Subordinate Theme	Clustered Emergent Themes	Examples of Quotes
'Normalisation' and opportunities/ Community Presence	Flexible routine (84-89) Moving on to independence (13-14) Desire for independence (55-57) Opportunity to attend college (65-66) Opportunity to engage in leisure/social activities (70-72) Access to leisure and social activities (85-89) Opportunity to go on holiday with AP family (97-99) Increase in choice and opportunity at AP placement (230-237) Shopping activities (264-267)	*"First I lived with my Mum first and then I wanted to move on from Mum's to be more independent myself…" (13-14)* *"It's not that I don't love her [Mum], it's just I wanted my own…not space…but my own independence, going places, you know. You know what I mean, I do that, go on the bus to [name of area], I have a look around the shops and then come home…" (55-57)* *"Well it's like, sometimes it's on a weekend and sometimes it's on week days, what it's like see, is sometimes they do sessions and take people out, Monday – me and Ann [fellow service user] go out with [AP carer] for tea look, on a Monday. And on a Tuesday night, they either pick me up from college, and we come home and then we go to club in [name of area], but Wednesdays my day is busy 'cause I go bowling, but not tonight 'cause it was the last one on the 10th look, 'cause I had a Christmas meal out and the opera I did." (84-89)* *"And we go away on holiday, we go to Pontins or we go to Cornwall, it all depends, we go, like, [Carer 5] and [carer's spouse] will book them and I pay them wherever we stay, we stay like in a chalet or apartment we do. They work out how much it is and then I give the amount of what it is." (97-99)* *"Well before I lived here I was living with Mum. I used to go out but not far, but since I lived here I do go out. I go to college three days a week, on the bus myself, then I go to sometimes to [name of area] sometimes, not all the time but if I need anything I can go like. Or like, if I, go out I can go out with them [AP carers], it all depends see. I go out, well if I want to go out I go out, or I can stay in…" (230-234)* *"Like, we go shopping, we go like um, Christmas shopping or like shopping for ourselves, not just food but we have a girly day shopping and sometimes if Elenor ain't busy with all her gigs and that, she comes with us. But if she's busy she can't like but she comes if she can. Our favourite*

		shop is Pri…Primark, do you like that?" (264-267)
Choice	AP is what SU wanted (360-372) Deciding on AP (14-18) Decision-making (353-356)	"…then, like um, like Social…you know like Alys, Social Services, then they found, then Alys found this here, for me to….first I was gonna come here on a respite, to try it but then I wanted to like live here, so then I come then to….I came with Alys and Carol, who's a Social Worker, both of them brought me here for me to visit. And then I was supposed to come for respite but then I decided I just wanted to live here so I moved in." (14-18) "…so Alys and Carol – who was a Social Worker I used to have, they both then found this place for me then I came to visit here ,then I was supposed to stay just on respite for a few weeks or months, then I decided then to live here. I decided then I'm not moving out, I wanted to live here. And in the end I had a chat with [Carer 5] and the family…" (353-356) "What is was, my Social Worker, Carol and Alys, they both brought me here, and introduced me to [Carer 5] and [carer's spouse], and then 'cause I wanted to live here…Alys then had to speak to her [Mum] and explain to her that [Service User 5] wanted to move out, but it was a bit hard I know, she didn't want me to go see 'cause I was like her little girl and she didn't want me to go, but I wanted, it weren't anything to do with my Mum, I wanted my own independence, well not freedom, but you know what I mean…to go out and about and meet people and be socialising…" (360-368)
Improved Quality of Life & Building Relationships	Positive aspect of AP in comparison to previous experience (42-49) Life changing (347-350), (519-522) Relationship with other SU at AP (189-193) Increase in confidence supported by AP carers (218-228) Friendships developed since being in AP (247-250)	"Karin: OK, what do you like about living here? Service User 5: I like the different atmosphere. Karin: Yeah, what's different about the atmosphere? Service User 5: It's different living with me Mum, to living with [Carer 5] and [carer's spouse]. Karin: So it's different, is it good different… Service User 5: I find it better here, I'm not being nasty, but I just find it, the surroundings better. Karin: Was it more difficult living with your Mum? Service User 5: Yeah." (42-49) "The thing is though, without them, I wouldn't know where I'd be, 'cause they took me into their home, 'cause, you know, I used to live with my Mam, like, and my Mam used to move about into

Spending time with fellow SU (515-516) AP family important to SU (131-133) Feeling nervous when meeting new people (198-200) Uncertain at the beginning (212-219) Transition to AP (360-368) Nervous at first (414-415) Experience of friendship (269-280) Getting on better with Mum now (442-447) Previous conflict with Mum (449-453) Learning about continuity of Relationships - Rupture and repair within relationships (311)	*different houses and all that, and I came here 'cause I was like a sort of emergency respite…"* *(347-350)* *"The best thing? It's changed my life around… When I lived with my Mum, I wasn't so happy, now I live with [Carer 5], I'm more happy than I've ever been." (519-522)* *"Well you do get nervous when you meet people for the first time and you don't know them, you do get nervous, and then once you get to know them, you're alright." (198-200)* *"Service User 5: I was a bit quiet and shy with the family as well, when I first come here, look, in their cupboards, I used to ask all the time.* *Karin: Whether you could get something?* *Service User 5: Yeah, but now I just go in there and do it. But when I first moved in I was a bit shy about going in their cupboards. I used to ask all the time, [Carer 5] will tell you that, I used to ask constant, but now I don't now.* *Karin: What is different now?* *Service User 5: I think it's my confidence." (212-219)* *"I was a bit nervous, like, and I think she might have been a bit nervous meeting me, what I were like…" (414-415)* *"Karin: …how do you get on with your Mum now? And is it different to how you got on when you lived with her?* *Service User 5: Not so well as we do now. We used to argue all the time, innit, sad mind like that innit.* *Karin: So moving out, although it was hard, was good for your relationship too?* *Service User 5: Yeah, we don't argue so much now." (442-447)* *"She's used to it now see, before she didn't want me to come here, she wanted me to go back to her and I said No 'cause I wanted to stay here. In the end now she's okay with the idea now, she's used to it. At least I see her once a month now. We arrange, [Carer 5] rings her and we arrange a day and time and we go to the café and then I meet my friend after." (449-453)*

|		*"Me and my friend, Joanne, can argue and then next minute we're friends again."* (311)
Family Dynamics and Boundaries	Closeness to AP family (425-437) Living with a different family can be difficult (523-524) Notion of family at AP (207-209) Integrated into AP family (252-259) Bonding with the family (295-297) Notion of family bond vs. role of carer (326-340) In comparison to relationship with Mum (386-393)	*" Well, now we're like sisters"* (209) – talking about fellow service user at AP *"And Elenor is like that too. And I have like with Matty, and Lydia and George, I have bonded with them as well, through like [Carer 5], I have like, I like them a lot…I think that's like a family circle or tree, like. I know they're not my family, I know that, but what I mean is, it's hard for me to grasp why I've bonded more with [Carer 5] than I have Joanne, my friend. Normally, it would be the other way round innit. You bond more with your friends than you would a carer, but I can't grasp it how I've bonded more with [Carer 5]. I'm not being nasty about my friends, I like Joanne and her mum, it's just I bonded more with this family than with my friends.* *…It could be that I live with them, well apart from Matty, Lydia and George but George did live here when they were younger, but he moved on, and now he's got his little family like.* *Karin: But you're all part of a bigger family…* *Service User 5: Yeah."* (326-340) *"It's just that my Mum didn't want me to go, well all mum's are like that, you know, all Mum's would be like that, they just playing their role, their bit, their role as a Mother…Perhaps she found it hard with me gone, perhaps she thinks I don't sort of love her but I do, it's just I wanted just get out there and meet people to talk to. I know I can talk to mum and all that but thing is if you're in a bedroom for a long time, you ain't gonna know anyone.""* (386-393)
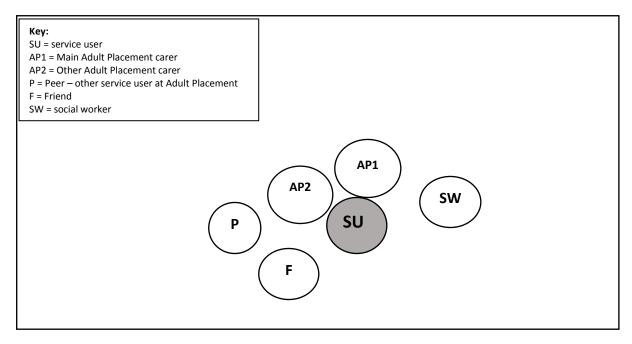
AP – differentiated to other forms of care	The same but different (AP and respite) (500-509) Previous isolation (390-393) when living with Mum Restricted life with family of origin (371-375) Previous isolation and restricted life (122-124) Previous experience (348-350) Uniqueness of AP (342-343)	*"Karin: Is there anything different about being there [respite] compared to here [AP]?* *Service User 5: I'd say it's just the same* *Karin: Just the same, okay, what is it like when you're not with [Carer 5] and the family?* *Service User 5: It's different then, 'cause you're not…they're different carers.* *Karin: What's different about it?* *Service User 5: It's different surroundings, not atmosphere but surroundings.* *Karin: Do you miss being at home when in respite?* *Service User 5: Sometimes…but I enjoy it.* *Karin: So you enjoy being there but you can also miss being at home.* *Service User 5: Yeah." (500-509)* *"Perhaps she found it hard with me gone, perhaps she thinks I don't sort of love her but I do, it's just I wanted just get out there and meet people to talk to. I know I can talk to mum and all that but thing is if you're in a bedroom for a long time, you ain't gonna know anyone." (390-393)* *"they are like my family, not, well, like foster family, like, well not adopted either, but like, adult, like…I can't think what to call it…" (342-343)* *"…Because if you're stuck in a bedroom for 24 hours you ain't gonna meet anybody... It's not healthy is it? I think my Mum wanted me though lo…well not locked up but didn't want me going out anywhere…" (317-375)*
Reciprocal care and support	Being looked after by AP carer (20) Maintains contact with AP carer whilst away from home (57-60) SU and AP carer worry about each other (62-64) SU considerate of AP carers feelings (287-293) SU considerate of AP carer's	*"…and then I text [Carer 5] to say I'm on my way home. It's just a thing I've got used to, not all the time but if I'm out and about I will text just to say I'm on my way home, she likes to know I'm safe see, my safety innit…If I don't ring or text she'd be worried innit, so she'd like worry where I am. So when I come home from college I always text to say I'm on my way home, 'cause otherwise if I don't do it I know I'd worry too." (57-64)* *"Sometimes, you know, we have 'moments', but not all the time, you know what I mean, like, if she's probably tired, like sometimes, not all the time though, it's just, I always, sometimes, let them have their space. Like if they are watching telly, I will go to my room and I watch telly.*

	multiple responsibilities (379-382) Considerate of AP carers (298-305) Positive affirmations of support from AP carer (468-470), (487) Keeping safe (511-513) Support received from AP carer (101-109), (112-116), (415-419), (400-405) Advice from AP carer (116-118), (472) Support from AP carer to maintain relationship with Mum (174-178), (376-379), (452-453)	*Sometimes I sit in the room with [Carer 5] and [carer's spouse], and watch telly with them, 'cause they got a fire in there and they like to light the fire, you know, or sometimes, if they want a bit of time to theirselves I can go to my room and watch telly, you know. (287-293)* *"…what it is, I got my money tin, and what [Carer 5] does, she helps me put in Week 1 and Week 2, to sort it out…she does put my money like, if I want to save for Avon, she puts it to one side or if it's something else, and she comes to the post office with me when I draw my money out and then I put it in my zip part of my bag and then when we come back we sort it out. I bring my tin down and I've got a grey book I have and I write down my money in there, you know, like things I have to pay out, like, my phone, or like, well not phone, but do you know what I mean?" (101-109)* *" …what it is though, she's helped me with my repeating problem as well, what it is, I've a repeating…I repeat things, I say the same thing again…She has helped me…she helps me recognise when I've said something twice…she will tell me." (415-419)*
Feeling closest to AP carer	Bond with AP carer (282-285) Stronger bond with AP carer (313-321) SU feels closest to AP carers (150-155) SU spends most time with AP carer (260-262)	*"Karin:…Can you tell about what your relationship is like?[with Carer 5]* *Service User 5: Um, (.) I'd say it's a good thing…I've, like, bonded with [Carer 5].* *Karin: So you feel like you have bonded with her, how to you get on with her?* *Service User 5: We get on good." (282-285)* *"You see, me and Joanne, are sort of good friends. But it's hard to explain how, like, from a good friend to a carer, now I don't know what the different is. I know Joanne is my good friend but I don't know why, what it is, I've bonded more with [Carer 5] than my friends. I don't understand why." (313-316)*
Availability and Involvement	SU and AP carer doing things together (68-72), (264-267) Positive attributes of AP carer (409-411)	*"We go to the cinema, we go, I go to shows with [Carer 5], to the theatre and we go with the hair…with the local hairdressers down the road and we go on a coach trip to…it's either Cardiff we go or Bristol look, the Hippodrome? It's either one or the other look." (68-72)*

Providing a 'safe haven' -	SU talks to AP carer when worried (471-472) Able to go to AP carer for help in a difficult situation (481-483)	*"Karin: Does she help you if you're upset or worried about anything?* *Service User 5: Well I do talk to her. I worry about anything. And [Carer 5] advises me." (471-472)*

Appendix XXII: An Anonymised Example of a Relationship Circle Exercise

Analysis of Relationship Circles Exercise and Semi-Structured Interview

Relationship circles exercise:

Key:
SU = service user
AP1 = Main Adult Placement carer
AP2 = Other Adult Placement carer
P = Peer – other service user at Adult Placement
F = Friend
SW = social worker

Interpretation of exercise:

The service user identified five people as important to and close to them. They appeared to understand the concept of the exercise and was able to differentiate levels of closeness. The service user identified feeling equally close to both Adult Placement carers, however in the narrative described spending more time with the main Adult Placement carer than with the other. The main Adult Placement carer was interviewed and identified feeling closest to the service user.

The service user named Adult Placement carers first.

The frequency of contact with the social worker appeared to impact on the placement of the social worker further away from the Adult Placement carers.

The service user talked about members of family of origin during the interview but chose not to put them on the exercise. The service user identified them as important; however, does not feel close to them due to some difficult experiences in the past. Some family of origin members had now passed away and the service user does not see others and feels they do not bother to keep in touch.

The friend that the service user identified was a neighbour that they knew when previously living with the family of origin. The service user made contact with the friend since living at the Adult Placement and visits the friend regularly

There are few people on the service user's relationship circle exercise. This may be indicative of there being only few people who the service user identifies as being important and feels close to. The interview with the Adult Placement carer revealed that the service user also has contact with wider Adult Placement family members and people within the local community who know the service user. It is possible that the service user does not identify such people as important and close, or may have required further prompting to consider them.