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Adult Family Placements: The experiences of Carers in Learning Disability Services

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ABSTRACT

The shift in learning disability services from institution to community settings has been mirrored by the development of new types of respite, short and long term care for individuals with a learning disability. Adult Family Placements are provided by individuals or families in the local community, who share their homes and their lives with people with learning disabilities who need support to live more independent lives. In recent years there has been growing interest in the provision of family-based schemes (McConkey, McConaghie, Roberts & King 2002), and such schemes are now widely used for the provision of long term residential care for people with learning disabilities in Britain (Dagnan, 1997). While a limited amount of research has focussed on the characteristics of providers of Adult Family Placements (Gage, 1995; McConkey *et al.*, 2005), and some has focussed on the recruitment and retention of such providers (Bernard, 2004; Hanrahan, 2006), very little research has focussed on the reasons behind why people become providers of such placements (McConkey *et al.*, 2005). The aim of the present study was to use qualitative methodology to explore the experiences of five individuals who provide Adult Family Placements for individuals with a learning disability. Information was gathered using semi-structured interviews and verbatim transcripts were then analysed using Interpretative Phenomenological Analysis (Smith, 2004). From the analysis, five superordinate themes emerged, each with their corresponding master themes. The superordinate themes were 'motivation to provide a placement', 'notion of family', 'scope of role', 'emotional investment' and 'personal-professional issues'. These themes raised a number of important clinical and service considerations concerning the recruitment, training and retention of Adult Family Placement providers. The implications of the study for both services and clinical practice are discussed and recommendations made.

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CHAPTER ONE: INTRODUCTION

1.1: Synopsis

This research aims to investigate the experiences of individuals who provide Adult Family Placements for people with a learning disability. Specifically, the research aims to explore participants' reasons behind becoming Adult Family Placement providers, the rewards and challenges of providing such a placement, and the impact that the experience has on the individual carers. In order to account for the need for such a piece of research, this chapter will provide an overview of existing literature in relation to the area of Adult Family Placements.

This chapter introduces the topics and research that are relevant to the current study. Initially, definitions and descriptions of learning disability will be provided, as this study focuses on Adult Family Placements for this group of people. A brief overview of the development of learning disability services will also be provided, and the contexts in which people with learning disabilities live will be briefly outlined. Key to the success of these services is the role of care staff. Therefore, their role, and the impact the role has on them in terms of the experience of stress, will be outlined. The potential for attachment relationships to develop between staff and service users will also be discussed. An overview of Adult Family Placements will be provided and the relevant literature will be outlined. Issues in relation to respite will also be outlined. The nearest comparable provision to Adult Family Placement appears to be foster placements for children and young people; this is the only other provision where carers work with and share their home with the people they support. Therefore, some of the literature on the experiences of foster carers will be briefly outlined. Finally, the aims and objectives of the current study are presented.

1.2 The Process of the Literature Review

A comprehensive literature review was carried out via key databases and search engines to explore the areas of interest relevant to the current research. These included OvidSP; (Psychinfo, Psycharticles, EMBASE, AMED [Allied and complementary Medicine], EBM

Review [Evidence Based Medicine Review); Proquest (ABI/INFORM Global, Dissertations & Theses: A&I), SCOPUS, Swetwise, Sciencedirect, Wileyinterscience and IngentaConnect, Informaworld, and Google Scholar.

The key search terms that were used were “Adult Family Placement”, “shared living”, “long term care”, “community placements”, “family Carers”, “Staff”, “Paid carers”, “Adult Placement”, “foster carers”, “foster placement”, “carer/staff stress”, “burnout”, learning disability”, “intellectual disability”, “learning impairment” and “cognitive impairment”. The researcher used both ‘and’ and ‘or’ to combine the search terms; for example, “learning disability” or “intellectual disability” or “learning impairment” or “cognitive impairment” and “Adult Family Placement” or “Adult Placement” or “shared living” . These terms were truncated to increase likelihood of search hits and were also searched together with related terms where possible. The researcher undertook the process of accessing the pertinent references and citing studies that were of relevance to the current research. When the option of searching for ‘related articles’ was available on the search engine, this was also completed.

Service-related documents were accessed via the websites of the Department of Health, National Health Service and the Welsh Government. The researcher identified generic themes which have been the focus of research with this population. The most relevant literature pertaining to Adult Family Placements was then discussed in this review. The titles and abstracts of studies were examined against a set of criteria and were excluded based on the following criteria; not published in the English language, based on the experiences of professionals only and relating to unpaid family of origin carers. This process highlighted the fact that there is a wealth of literature of relevance to paid care staff supporting people with learning disabilities in a variety of settings. However, by comparison, there was a scarcity of research investigating Adult Family Placement Schemes, in particular the carer experiences. The researcher also contacted a leading author in this area (R. McConkey) who confirmed this.

Although some research has focussed on the characteristics of individuals who provide placements, this tends to be quantitative in nature. Most of the research identified in the area of Adult Family Placements was in relation to recruitment, retention, and respite breaks for families. The literature review therefore confirmed that qualitatively exploring people’s experiences of providing Adult Family Placements was an original and relevant focus for

research. Following completion of the data collection and analysis, a further literature search was completed to identify the literature that was relevant to themes that had been identified from the analysis, and which would inform the write up of the literature review and discussion of the research.

1.3 Learning Disability Definition and Criteria

People with learning disabilities form one of the most vulnerable groups of people in society. Such individuals vary significantly in the degree of their disabilities. This variation means that there needs to be a variety of support available designed to meet the specific needs of the person (Carnaby, 2007). The terminology used in the UK to label people with learning disabilities varies significantly between organisations and situations. ‘Intellectual disability’ is the term adopted internationally, mostly in the academic literature, whilst in the UK the most commonly used term by the British Government and in professional and academic circles is ‘learning disability’ and people with ‘learning disabilities’ (Beadle Brown, Mansell, Cambridge *et al.*, 2004). The term ‘learning disability’ is therefore used throughout the current thesis.

A diagnosis of a learning disability is given when an individual meets three important criteria, in that they have:

- A significant impairment of **intellectual functioning**, as well as
- A significant impairment of **adaptive/ social functioning**, and that
- Both of these impairments were **acquired *before* adulthood**

(British Psychological Society, 2001; Emerson, Hatton, Felce *et al.*, 2001)

1.3.1 Level of intelligence

The principal method for determining an individual’s level of intelligence is psychometric assessment. Assessments which are based on an explicit model of normal distribution of general intelligence are the procedures of choice. Assessment of general intellectual functioning for clinical, medico-legal and other purposes, should be made through the use of

an individually administered test which is recognised as being reliable, valid and properly standardised.

Using tests based on a normal distribution of general intelligence, significant impairment of intellectual functioning has, by convention, become defined as a performance more than two standard deviations below the population mean. On the Wechsler Adult Intelligence Scale – Fourth Edition WAIS IV (2008), the mean is 100 and the standard deviation is 15. More than two standard deviations below the mean thus corresponds to an Intelligence Quotient (IQ) of 69 or less (BPS, 2001).

1.3.2 Adaptive/Social functioning

The concept of adaptive/social functioning is very broad and relates to a person's performance in coping on a day-to-day basis with the demands of his/her environment. It is, therefore, very much related to a person's age and the socio-cultural expectancies associated with his/her environment at any given time. Assessment of adaptive functioning is concerned with what a person does in terms of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health and safety. In order to meet the criteria for adaptive functioning, the individual requires significant assistance to provide for his/her own survival and to adapt to the needs of his/her social and physical environment (BPS, 2001). Having a significant impairment in adaptive/social functioning suggests that the individual would need a significant level of support from services (Carnaby, 2007).

1.3.3 Acquired before adulthood

For a person to be diagnosed with a learning disability, significant impairments of intellectual and adaptive/social functioning must have been acquired before the age of 18 (BPS, 2000). However, it is more often the case that most learning disabilities are present at birth and if not, develop during early childhood (Carnaby, 2007).

1.3.4 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, Fourth Edition*, American Psychiatric Association, 1994; *International Classification of Diseases, Tenth Edition*, World Health Organisation, 1992). Although these systems employ the same descriptive categories, the quoted IQ ranges do not correspond exactly. The British Psychological Society (2001) recommends that decisions involving sub-classification of learning disability should make reference to both intellectual and adaptive/social functioning using particular criteria. For intellectual functioning, ‘significant impairment of intellectual functioning’ may be applied to individuals with an IQ of between 55 and 65 and ‘severe impairment of intellectual functioning’ is applied to individuals with an IQ of below 55. For adaptive/social functioning, ‘intermittent and limited’ support indicates a significant impairment of adaptive/ social functioning and ‘extensive and pervasive’ support indicates a severe impairment of adaptive/ social functioning (BPS, 2001).

1.3.5 Learning disability and co-morbidity

Evidence from epidemiological studies suggests that individuals with a learning disability are more susceptible to mental and physical illness than the general population (Prasher & Kapadia, 2006; Emerson, 2003; Cooper & Bailey, 2001). The reasons for this include biological and psychological risk factors. When considering prevalence rates, it is important to recognise the heterogeneity of the population, and the inherent difficulties in conducting high quality epidemiological research with people with learning disabilities. However, the increased risk of ‘other’ disorders demonstrates the importance of appropriate service provision and support for adults with learning disabilities (Cooper & Bailey, 2001).

1.4: Estimated prevalence of learning disability

It is estimated that approximately 2% of people in the general population have a learning disability (Foundation for People with Learning Disabilities Web Archive). However, it is not possible to accurately estimate the number of number of adults with learning disabilities in UK either from information held by central government departments or from large-scale

population based surveys (Emerson & Hatton, 2008). For example, in Wales, there are published up-to-date figures of the total number of adults with learning disabilities, but these only reflect those individuals who are receiving a service (Welsh Assembly Government, 2011a). What is known is that there are increasing numbers of people with a learning disability. Firstly there is an increase in the incidence of learning disability, related to increases in maternal age and improved survival of infants due to improvements in pre- and post-natal care (WAG, 2001) Secondly, and by far the most significant factor affecting the number of people with a learning disability, has been increased life expectancy. In a more recent report (Emerson & Hatton, 2008) it was highlighted that these demographic changes were likely to impact on the need for services for people with learning disabilities, with individuals and their families requiring different systems of support. A shift in support from informal support networks to more formalised systems of care is likely to arise, and a range of influential factors exist. These include, an 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, 2008).

1.5 Development of learning disability services and relevant policies

During the last 40 years there have been many changes and developments in care provision for people with a learning disability. One of the major changes has been a move from institutional care to the provision of a range of community based services. The focus of care has gone from security, protection and uniformity to the gradual realisation that even those with profound and severe learning disabilities have the right to as normal a life as possible. This was a significant shift in attitude considering that, historically institutional care was seen as a means of containing people who were seen as worthless and unable to contribute to society (Carnaby, 2007).

However, it was not until the 1980's and the Community Care Act 1990, that a clear pathway for making provision in the community was outlined. The NHS and Community Care Act (1990) gave health authorities the responsibility for assessing the needs of the population they served and for purchasing services from providers through contracts to meet those needs (Watters & Murphy, 1996). It was estimated that in 2001 approximately £3 billion per

annum was spent on specialist services for people with learning disabilities in England and £130 million by local authorities in Wales (Emerson *et al.*, 2001).

Amongst the most influential of documents on the development of service provision for people with learning disabilities in the UK was the 'Valuing People' White Paper (DoH, 2001). This recognised the need for people with learning disabilities to lead fulfilling lives as well to receive help from high quality services. This document introduced four key principles related to people with learning disabilities: rights; independence; choice; and inclusion. Since this time a newer version, 'Valuing People Now' has been published and continues to work to the above four key principles (DoH, 2009).

In Wales, the development of alternatives to institutional living became widespread following the launch of the All Wales Strategy for the Development of Services for 'mentally handicapped' people (Welsh Office, 1983). Such policies promoted ordinary lifestyles for people with learning disabilities in Wales and recognised the rights for broad ranging support based on individual need (Todd, Felce, Beyer *et al.*, 2000). Following on from this, service development in Wales was influenced by 'Fulfilling the Promises' (WAG, 2001), which set out the vision for services for PWLD. The vision outlined was that by 2010 services for people with learning disabilities in Wales should: provide comprehensive and integrated services; be person centred; improve empowerment and independence; ensure effortless and effective transition between services and organisations; be holistic; have a range of advocacy services; be accessible; have fully developed collaborative partnerships and finally, be delivered by a competent, well-informed, well-trained and effectively supported and supervised workforce (WAG, 2001). Other health and social care policy documents in Wales, for example, 'Designed for Life', have also stated that their vision is to 'shape services around service users' (WAG, 2005).

In the UK, larger institutions were firstly replaced by homes of twenty five to thirty people in the community and later with smaller staffed homes, usually with seven or eight people in older homes and two to six in newer homes (Mansell, 1996). This was influenced by the idea that a move to an 'ordinary' life service model, with small well furnished community-based homes, in ordinary streets, with staff who have received appropriate training, would produce a new, more fulfilling lifestyle for people with learning disabilities (Kings Fund, 1980).

Since this time, small scale community provision has expanded considerably (Perry, Lowe & Felce *et al.*, 2000).

Over the years, many comparisons have been made between community and institutional provision and between different models of community provision. Generally, the result has been that any model of community care provides better quality of care and therefore a better quality of life than institutional care (Emerson, Robertson, Gregory *et al.*, 2001, Perry & Felce, 2003). It is estimated that approximately half of all adults with learning disabilities live with their families, while the other half live in residential provision (Carnaby, 2007); of those in residential provision, the dominant form of accommodation for people with learning disabilities in the UK is now small community based supported housing (Wilkinson *et al.*, 2005). Current models of community residential provision include hostels, group homes/ staffed housing, specialist residential services supported independent living, and family placements. In Wales, the number of people with learning disabilities residing in such facilities provided by local authorities and the private and voluntary sector increased significantly between 1990 and 2005 (WAG, 2007).

However, it is important to note that community-based residential provision does not guarantee a better quality of care and quality of life for adults with learning disabilities. Baker (2007) emphasised the relatively impoverished range of community and leisure opportunities for people with learning disabilities even after moving from hospital. McVilly, Stancliffe, Parmenter & Burton-Smith (2006) noted that there are a number of people with learning disabilities who cannot be considered as part of the community in which they live; tending to have fewer friends than adults without learning disabilities. Even where individuals have their own tenancy in a community, many tenants find themselves more socially isolated than they had been when they lived with their family or in a large institution (Jackson, 2011). Perhaps more than any other group, *'people with a learning disability are vulnerable to social exclusion and discrimination'* (WAG, 2007). People with learning disabilities are less likely to marry, more likely to be unemployed, have less say about where and with whom they live (Mansell & Beadle-Brown, 2010). Therefore, despite great progress and developments within learning disability services, it is clear that there is still work to be done in attempting to improve the quality of life of the individuals who rely on them.

1.6 Normalisation

The development of community learning disability services relied on a number of key ideas, one of which is normalisation (Wolfensberger, 1972), the principle of which has largely shaped service provision for individuals with a learning disability. Care plans, operational policies, training in good practice - everything to do with quality provision has normalisation at its foundation (Carnaby, 2007). 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 in society'

(Nirje, 1980).

The development of normalisation became a way of encouraging services to create a positive image for and with people with learning disabilities (Wolfensberger, 1972). Interpretations of normalisation in Britain tend to use O'Brien's five service accomplishments to inform services:

- 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 image 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, i.e. ensuring that ‘service users participate in the life of the community’.

(O’Brien & Tyne, 1981)

Whilst normalisation has been very influential, it has also been heavily criticised for a number of reasons. Among these criticisms are the fact that its value base accepts inequality within society without addressing the causes of social inequality and exclusion, that its principles are based on middle-classed societal norms and its implication that people with learning disabilities are not ‘normal’ (Bradley, 2005).

1.7 Quality of Life

The shift in policy from residential provision in institutions to provision in the community has been accompanied by far greater emphasis on the quality of services provided (Perry & Felce, 2003). Although social isolation was inevitable with institutionalisation practices, this still persisted with the move to community-based accommodation (Emerson & Hatton, 1996). Historically, the evaluation of outcomes for service users and services has been somewhat narrow in its focus, with outcome measurement usually focusing on interaction, skill acquisition and reduction in maladaptive behaviour (Felce, Lowe & Blackman, 1996). However, the focus has since changed, with contemporary service philosophies frequently expressed in terms of ‘quality of life’. There is now recognition that quality of life is a multi-dimensional construct that concerns the whole of an individual’s life, and one that applies to the general population, not just particular groups of individuals (Felce, 1997; Felce and Perry, 1999). Quality of Life is seen as reflecting 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. Inherent in each of these domains are the assessment of objective and subjective lifestyle indicators (Felce, 1997; Perry, Lowe & Felce, 2000). The importance of maximising the ‘quality of life’ of people with learning disabilities is frequently referred to throughout the literature, and is at the heart of many government policy documents.

However, the switch to community provision from institutionalisation does not necessarily result in a positive impact on quality of life. This has been found to vary depending on the type of provision, with a general consensus that smaller more individualised options are of greater benefit (McConkey, 2007).

1.8 Adult Family Placement Schemes in Learning Disabilities

As mentioned earlier, the shift in learning disability services from institutional to community settings has been mirrored by the development of new types of respite and short and long term care for individuals with a learning disability. One type of provisions is that of Adult Family Placements; it could be hypothesised that such placements are well placed to maximise the quality of life for the individuals that they support.

Adult Family Placements have been in existence for a number of decades (Feidler, 2004). At their most basic, they provide accommodation and support in an ordinary home for someone who needs support (Bernard, 2004), thus supporting ideas of an 'ordinary life' in an 'ordinary community' (Kings Fund, 1980) for people with a learning disability.

A national survey carried out in 1988 found that 54% of social service departments in Great Britain ran family placement schemes providing long-term care for adults with learning disabilities (Dagnan, Nagel, Thompson, Drewett *et al.*, 1990). However, it is only more recently that these schemes have begun to attract attention in the literature (McConkey, McConaghie, Roberts & King 2002). Such schemes are now being widely used for the provision of long term residential care for people with learning disabilities in Britain (Dagnan, 1997). This may be because of their place within the community where evidence suggests that services are able to provide a better quality of care and therefore a better quality of life than institutional care (Emerson, *et al.*, 2001, Perry & Felce, 2002). Government strategies for providing services for people with learning disabilities are continuing to work to the four key principles of: rights, independence, choice and inclusion. It could be hypothesised that the Adult Family Placement model of provision is ideally placed to promote and support these key principles.

Adult placements are provided by individuals or families in the local community, who share their homes and also their lives with people with learning disabilities who need support to

live more independently. Such schemes, and their carers, provide a form of support that is increasingly recognised as a valued and flexible service option by both carers and service users alike (McConkey, McConaghie, Roberts & King 2002; Bernard, 2005). A 2004 UK survey revealed that there were approximately 5000 Adult Family Placement Carers and 6,500 service users supported in such accommodation (Feidler, 2004) , however it is likely that these figures have increased since this time.

Historically, family placements were defined as, *"a scheme in which one, two or three adults with a mental handicap are found a home in an existing household of non-handicapped people, which is intended to be permanent"*. (Dagnan *et al.*, 1990). The Department of Health policy and practice guidance for Adult Placement Schemes captures this earlier definition, but also adds to it the notion of extended family ('kinship') support in the community (Department of Health (DOH), 2002).

Adult Family Placements provide a unique form of care and adult placement carers are characterised by their relationship with their scheme and service users. Typically, carers are not employees of adult placement schemes. For a set fee, they undertake to provide, as near as possible, a family setting for service users, somewhat akin to 'adult fostering' (NAPPS, 2004).

1.8.1 The policy context

The National Minimum Standards (NMS) and regulatory framework within which Adult Family 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 (DoH, 2003). However, there was a concern at this time that the regulatory system led to a loss of carers, due to the added burden placed on the individual carer (Bernard, 2005). To address this problem, regulations and NMS for adult placements have been revised (DoH, 2004), and this has shifted the focus of registration and inspection to schemes rather than individual carers. The Welsh Government also published guidelines which supported the regulation for Adult Placement Schemes, rather than the individual carers (WAG, 2004).

The following themes underpin the drafting of the regulations and National Minimum Standards for Adult Placement Schemes (DoH, 2004). In order to apply the standards inspectors need to look for evidence on a number of themes:

- Focus on individuals- to look for evidence that Adult Placements lead to positive outcomes for and the active participation of individuals, and are consistent with the principles of rights, independence, choice and inclusion.
- Fitness for purpose- to look for evidence that a scheme is successful in achieving its stated aims and objectives and meeting individual needs.
- Comprehensiveness- to consider how the service offered by the placement contributes to meeting the person's overall needs and preferences, and how the scheme and carer work with other services and professionals to ensure a normal life in the community for the individual.
- Positive choice- to look for evidence that people are placed with a carer, and remain in that placement, because that is where they want to be and where their needs can best be met
- Meeting assessment needs - to look for evidence that the placement meets the person's assessed - and changing- needs
- Protection- to look for evidence that the person is safe in placement and protected from abuse, neglect and self-harm.
- Commissioner responsibility- to look for ongoing involvement of social services care managers/care co-ordinators in the re-assessment and review of individual placements.
- Quality services- to seek evidence of a commitment by the scheme to continuous improvement and quality services, support, accommodation and facilities which assure a good quality of life for people using adult placements.
- Quality workforce- to look for evidence that registered scheme managers and staff comply with relevant codes of practice, and that carers have appropriate skills and experience for the tasks they are expected to do. (DoH, 2004)

1.9 The role of care staff in Learning Disability Services

Care staff are recognised as both a valuable and key element to the lives of people with learning disabilities (Rose, David & Jones, 2003; WAG, 2011b), providing one of the most important sources of support to people with learning disabilities and their families (Test, Flowers, Hewitt & Solow, 2004). Care staff have been described as the interface through which policies and procedures are translated into practical action that directly influences the quality of life of people with learning disabilities (Hatton, *et al.*, 1999). Care staff have to be in direct contact with clients all the time and often deal with a large group of clients simultaneously, while trying to implement specific goals (Mascha, 2006). It is widely accepted that the majority of care staff are women. Recent UK surveys have demonstrated a scarcity of male workers in learning disability services. One study found fewer than one in five male staff in both day services and supported accommodation (McConkey, McAuley, Simpson *et al.*, 2007) Similarly, it was estimated that approximately 80% of the social care workforce were women, which rose to 95% in some sectors, e.g. residential care (TOPSS, 2004).

Hewitt & Larson (2007) describe how the role of care staff now goes beyond that of the primary caretaker as it was in institutional care. Not only are care staff expected to meet people's basic health, safety and care needs, but they are also expected to support them in activities such as: developing and achieving personal goals, balancing risks with choices, finding and keeping jobs, connecting with peers, friends and family members and supporting service users to be full and active citizens in their communities (Hewitt & Larson, 2007). Staff are often the main providers of emotional support (Forrester-Jones *et al.*, 2006), acting as counsellor, friend, confidante and advisor to the people they support (Hewitt & Larson, 2007). Alongside this, 'Valuing People' (DoH, 2001) stated the need for care staff to be skilled, trained and qualified in order to work to these new principles; specifically they need to be 'well informed', 'well trained' and 'well supervised' to do their job. Workforce planning continues to be central in the Welsh Government's plans for developing services. Fulfilled Lives, Supportive Communities: A Strategy for Social Services in Wales over the next Decade (Welsh Assembly Government, 2007) underlines the need for an adequately sized, skilled and valued workforce, a large proportion of which includes direct care staff. However, the ability to find train and keep direct support staff is one of the biggest barriers to continued efforts to expand and sustain community supports (Test *et al.*, 2004).

1.10 The impact of 'caring' on staff

The quality and stability of direct support professionals are of fundamental importance to the well being of people with learning disabilities (Larson, Hewitt & Lakin, 2004). The behaviour of staff, in terms of assistance and positive contact, has been found to have a direct impact on the quality of life of people with learning disabilities (Felce & Emerson, 2001).

1.10.1 Stress

One important issue which has attracted much attention in the literature is that of workplace stress and its impact on care staff within learning disability services (Hatton *et al.*, 1999; Jenkins, Rose & Lovell, 1997; Mitchell & Hastings, 2001; Skirrow & Hatton, 2007). Psychological stress is considered to be a significant problem amongst staff working in this area, both because of its high prevalence rates and its potential implications for providing quality services (Skirrow & Hatton, 2007). Surveys of learning disability services suggested that between 25% and 32.5% of support staff experienced significant levels of stress (Devereux, Hastings, Noone, Firth & Totsika, 2009).

Evidence suggests that many factors influence the extent to which direct support staff feel stressed at work. These include staff coping strategies, client behaviour, and staff attitudes towards challenging behaviour. High organisational stress has been found in residences where there are high levels of role conflict, role ambiguity, and role overload (Dyer & Quine, 1998). Stress linked to work-home conflict has also been highlighted throughout the literature (Hatton, *et al.*, 1999; Hatton & Emerson, 1995). In the UK there is also evidence to suggest that caring for people with greater needs and challenging behaviour is associated with greater carer stress (Dagnan, 1994; Hastings & Brown, 2000).

Hastings (2002) reviewed the literature on the relationship between challenging behaviour and staff stress and concluded that there is a significant and reasonably strong association between staff exposure to challenging behaviours and staff stress. Hastings went on to suggest that the impact of challenging behaviour on staff can vary from minor irritation to debilitating fear and anxiety.

1.10.2. Burnout

Prolonged exposure to stress can contribute to 'burnout', a state characterised by '*emotional exhaustion, depersonalisation, and a lack of personal accomplishment at work*' (Devereux *et al.*, 2009, p. 368).

In their systematic review of the research into the burnout of staff working with people with learning disabilities, Skirrow & Hatton (2007) discussed the lack of coherent theoretical explanations for the relationship between stress and staff behaviour. However, they acknowledged that the notion of burnout had attracted particular appeal in learning disability services.

The primary focus of research in learning disabilities examines 'burnout' has focussed on challenging behaviour. Chung & Harding (2009) found a direct link between challenging behaviour and staff burnout in that a higher level of challenging behaviour was associated with increased emotional exhaustion and decreased personal accomplishment. However, the evidence of a direct link is equivocal and it is possible that a number of different variables mediate this relationship. Mills & Rose's (2011) study confirmed the link between challenging behaviour and burnout, but also found that staff perceptions about challenging behaviour mediated this relationship. They found that experienced staff who felt able to manage the behaviour, who exhibited less anxiety and felt like they were achieving something were less likely to experience burnout.

However, some authors have noted that stress and burnout is unlikely to be predicted entirely by factors relating to work (Hatton & Emerson, 1995), therefore the importance of other stressors, e.g. home life stressors are considered to be an essential factor. It is also important to note that not all carers report stress and burdens in caring. Dagnan (1994) found that some carers did not consider that the burden of care was greater than expected. It was suggested by these data that the effects of physical disability and challenging behaviour are mediated by the relationship between the carer and the person placed.

Hatton, Emerson, Rivers *et al.*, (1999) explored the factors associated with staff stress and work satisfaction in services for people with learning disabilities. Information was collected from 450 staff concerning general distress, job strain and job satisfaction. Role conflict and role ambiguity were found to be strongly associated with general distress. Additionally, lack

of staff support, especially for staff working in isolation, was strongly associated with job strain. This supports previous research which has found that staff support and role clarity may have a buffering effect on the perceived stress encountered by support staff (Hatton & Emerson, 1993).

1.10.3. Psychological theories of stress and coping

Individual personality and coping strategies are important factors to consider. It has been suggested in the learning disability literature that care staff who use adaptive coping strategies are less likely to experience high stress levels and burnout (Hastings & Brown, 2002; Rose, David & Jones, 2003).

Psychological theories of stress and coping may offer useful insights into the ways in which care staff working in learning disability services experience, approach and cope with the potential stress involved in supporting people with a learning disability. Theories of stress that focus on the specific relationship between external demands (or stressors) and internal bodily processes (stress) can be grouped into two different categories: ‘systemic stress’- based in physiology and psychobiology and ‘psychological stress’- developed within the field of cognitive psychology. Of these, psychological stress has gained the most support over the past two decades based on evidence suggesting that almost all stress experienced by humans is cognitively mediated (Lazarus, 1984).

‘Psychological stress refers to a relationship with the environment that the person appraises as significant for his or her well being and in which the demands tax or exceed available coping resources’ (Lazarus & Folkman, 1986, p. 63).

Lazarus (1966) argued that, in order for a psychosocial situation to be stressful, it must be appraised as such. He argued that the impact of the stressor is not dependant on the stressor itself, but the way in which it is construed by the individual. According to this theory, how a person reacts to stress depends on a two-phase appraisal process. The first is primary appraisal. Here, the individual perceives whether an event is harmful or threatening. Secondary appraisal involves examination of the available coping resources. According to Lazarus & Folkman (1984, p.141) coping is *“the cognitive, behavioural [and emotional] efforts to manage particular external and/or internal demands that are appraised as taxing or exceeding the resources of the person”*.

Coping researchers have tended to group coping responses into coping categories or styles. Perhaps the most widely accepted classification of coping strategies is *problem-focussed* and *emotion - focussed* coping (Lazarus & Folkman, 1984). Problem-focused coping involves cognitive and behavioural attempts to change the situation through modification of the environment, for instance, by gathering information and developing solutions in response to stressors. Emotion-focused coping attempts to regulate emotional responses in the situation, including escape and avoidance, or attempts to re-appraise the stressor so as to deal with the negative emotional responses that emerge. Research in learning disabilities has highlighted emotion-focussed strategies as a beneficial way of helping staff cope with workplace stress (Hatton & Emerson, 1995; Thompson, 1987; Hastings & Brown, 2002; Rose, David & Jones, 2003). However, Lazarus (2000) emphasised that although problem-and-emotion-focussed coping are conceptually distinguishable, they should not be considered independently and usually occur together.

A person's belief in their ability to perform in their caring role and manage the potential stress involved has also been found to be central in how they experience and cope with stress at work. A perceived competence to handle stressful situations has been labelled self-efficacy. Self-efficacy refers to people's beliefs about their capacity to control their own level of functioning and the events that affect their lives. Efficacy beliefs influence how people think, feel, motivate themselves, and behave (Bandura, 1994). According to Bandura, people who believe they can deal with stressors do not experience distressing thoughts, while those who believe they cannot deal with stressors experience high levels of anxiety. In other words, belief in one's capacities is associated with particular emotional experiences.

There has been very little research into the notion of self-efficacy as a mediator for staff stress when supporting people with learning disabilities. Preliminary studies have found a strong correlation between adaptive coping and levels of self-efficacy (Hastings & Brown, 2002; Cudre-Mauroux, 2010). However, these studies have been limited to staff experiences of working within challenging behaviour environments only and not within generic learning disability services.

Although there is research to suggest that many staff members have positive experiences and cope well when with working with people with learning disabilities, there is clearly a wealth of literature which highlights the increased risk of staff experiencing stress and potential burnout when working in this area. However, no studies have focussed directly on the

experience of stress and coping and its impact on Adult Family Placement providers. This issue would appear to be of particular importance, as it could be suggested that Adult Family Placement providers are at an increased risk of experiencing stress and burnout, given that they share their home with the individuals they support, providing long term 'round the clock' care.

1.11 Relationships between carers and service users

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. It could be hypothesised that the perception of care staff's role has always been to 'care for', rather than 'care about' service users and the subject of developing relationships with service users may be seen as somewhat taboo within the field of learning disabilities.

The quality of care given to people with learning disabilities is highly dependant on the staff who provide it, and direct care staff are in a position to bring out the best or worst in individuals with a learning disability (Hall & Hall, 2002). It has also 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).

Reinders (2009) argued that whilst being formally trained in the caring protocol and having expertise and skills in a certain area is beneficial, more attention needs to be paid to the relationship that develops between staff and service users. He recognised the importance of the dyadic nature of caregiving, and stressed that knowledge and skills of working with service users are the product of the interpersonal relationship that develops between the staff member and the service user. Although carers and service users interact on a daily basis, the quality of the relationship that develops is dependant on whether the carer is 'attached and attuned' (Reinders, 2009; p. 31) to the particularities of the service user.

1.11.1 Attachment Theory

Until fairly recently, notions such as attachment and attunement on a personal level with service users has been little discussed in the field of learning disabilities (Schuengel, Kef, Damen *et al.*, 2010). Within attachment theory, 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). Such emotional bonds may be reciprocal between two adults, but between a child and a caregiver these bonds are based on the child's need for safety, security and protection, paramount in infancy and childhood.

Bowlby stated that forms of attachment behaviour and the bonds to which they lead are present and active throughout the life cycle, “*from cradle to grave*” (Bowlby, 1979). Ainsworth (1989) similarly proposed that adult attachment relationships are characterised by a desire to maintain closeness to a partner, perceived as a unique individual and not interchangeable with any other, which results in feelings of comfort and security. According to Bowlby (1969), attachment bonds have four defining features: proximity maintenance, separation distress, safe haven and secure base. Attachment has often been misconceived as a developmental issue that is determined in early childhood (Schuengel, et al., 2010). However, attachment behaviour is associated with neurological changes which influence brain development and are therefore considered to be enduring over time (Waters *et al.*, 2000).

Attachment theory models differentiate between models for the attachment figure or carer and models for the individual receiving the care giving (Bartholomew, 1990). Bartholomew's system creates four possible attachment styles that predict the individual's reactions to distressing situations. These are: secure, preoccupied, dismissive–avoidant, and fearful–avoidant.

Sable (2007) suggested that 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. Conversely, lack of secure attachment can lead to difficulties in regulating emotions and relating to others, engendering a vulnerability to psychological distress. In relation to people with learning

disabilities, Hollins & Sinason (2000) suggest that the disruption in the early attachment processes may present a possible vulnerability factor for emotional difficulties. This is particularly concerning, given that as a group they are generally considered to be especially vulnerable to developing emotional difficulties (Prasher & Kapadia, 2006).

Clegg & Lannsdall-Welfare (1995) were the first to recognise the significance and value of the attachment perspective for the care of adults with learning disabilities. They drew upon attachment theory with the idea of developing interventions that would have a positive impact on service users' behaviours. Behaviours of concern were identified and understood in terms of attachment insecurity. These were intermittent and disproportionate expressions of anger or distress, resistance to exploring their physical world (e.g. refusing day trips and holidays) and completing tasks that were well below their cognitive abilities, significant 'fixations' on particular professional or family carers, and the person's anger or distress being expressed in selected settings.

The study delivered interventions based on providing support for carers who were overwhelmed by relationships that were difficult to manage with service users; building a secure base for the service user through the use of individual psychotherapeutic interventions and also helping staff members to develop their roles as a secure base for the person; and, finally, helping support staff to develop and manage their relationships with service users over the longer term. The authors reported that 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 number of people to whom the service user appeared to relate.

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. Moses (2000) looked at care staff in children's services and concluded that many of the strategies employed by care workers were consistent with the role of a 'secure base' and ultimately helped to promote a sense of being cared about, motivated the young person and enhanced self-esteem. The care workers also described as important a sense of 'attunement' to the changing needs, desires or characteristics of the individual. The importance of recreating a surrogate family for the emotionally disturbed residents was highlighted by the staff members' reference to their own roles as 'surrogate parents',

‘grandmother’ and ‘like a big brother’. Constraints to forming what were perceived by participants to be adequate relationships with individuals included personal factors such as attitudinal, emotional or experiential limitations, in addition to service constraints such as a low staff-client ratio and the agency’s strong emphasis on a structured, regimented programme that was not considered to be conducive to spending quality time with the individuals (Moses, 2000).

In the first study of its kind, Stimpson (2009) explored in-depth the relationships that develop between adults with learning disabilities and support staff. 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 highlighted the staff member as holding a special status, which in some cases was comparable to their relationships with a family member. This was similar to Moses’ (2000) study where staff members saw themselves as a ‘surrogate’ family for service users. The staff also distinguished the relationships from those that service users had with other staff, but also from the relationships that they themselves had with other service users. This distinction was apparent in the mutual closeness that was described, but also in terms of how they perceived the service users to show different, more positive regard and behaviour towards them.

The emotional content of the relationships described by the service users highlighted the affectional regard that they felt for the staff members, particularly in terms of missing them when they were not at work or contemplating a sense of loss if the staff member was to leave. Service users also recognised the staff member’s care and concern for them. The staff member similarly commented on the emotional content of the relationship, which revealed their own emotional involvement as well as their recognition of the emotional regard that service users feel towards them. It was noteworthy that the degree of emotional involvement sometimes caused staff to continue to think or worry about the service users when they were not on shift. The staff highlighted that the caring role is not something that they feel able to switch on or off, and they believed such care and emotional involvement is essential to their role. However, the author acknowledges a number of limitations of the research. Most importantly, the study employed a relatively small sample size comprising eight participants, which formed four interview dyads. This raises the question of whether the findings of

Stimpson's study are useful in developing an understanding of service user/ support staff attachments, other than those of the current participants. Nevertheless, this study provides important preliminary findings and it is important that this area of investigation is revisited.

Given their limitation in communicating emotional needs, it would appear that people with learning disabilities present as particularly vulnerable in terms of attachment. Care staff members who support them are therefore considered to be significant central figures in their lives (Schuengel, *et al.*, 2010). Although care staff receive training, and are encouraged to conduct themselves in a professional manner, they do not tend to be provided with guidance on how to manage their day-to-day, often close, relationships with service users (Pockney, 2006). This may be particularly problematic for Adult Family Placement providers, who live with the service users they support and are encouraged to treat them as an extended member of their family. The importance of training, especially around professional-personal boundaries, may be of particular salience for this somewhat unique group of care staff.

1.12 Adult Family Placement Providers

The success of Adult Family Placement Schemes depends largely on the recruitment of suitable people who are willing to offer placements in their own home (McConkey, *et al.*, 2005). There is a growing interest in this area, yet little research has been undertaken of the characteristics of the people who provide placements and the reasons for their involvement. There are two studies in the literature which look at the characteristics of those who provide long-term Adult Family placements.

A study conducted by Gage (1995) provided the first overview of carers who provide Adult Family Placements. He reported on sixty eight approved providers in an Adult Family Placement Scheme provided by Manchester Social Services. He found that a typical carer was female, middle aged, had grown up children and had previously worked in skilled and non-manual jobs within the health and social care settings. He also found that life-cycle position affected the motivation of people to become carers, given that they have to dedicate so much of their time to the role. One concern identified from this study was that at this time an undervalued section of society was being cared for by another undervalued sector, whose members did not have the strength of employee rights to protect them. However, there are

important limitations to take into account when considering the findings of this study. Firstly, because the database generated for this study was drawn from the personal files of placement providers, information relied on thorough and accurate records being taken, which may not have been the case. Secondly, it is important to note that the records were taken from a small number of people (n=68) and based in one area in England. This study also made reference to the 'enhanced quality of life' experienced by service users, but did not include any measures or empirical evidence for this. Despite its methodological limitations, it is important to remember that this study provided the first overview of Adult Family Placement Providers and served as a helpful base from which to generate future research.

The second, more recent study by Bernard (2004) identified similar findings. In a much larger study she looked at a total of 5001 carers who were part of 115 adult placement schemes throughout the UK. In line with previous research and statistics (Gage, 1995; TOPSS, 2004), her survey also found that carers were far more likely to be female (total of 74%) with almost all of the carers (95%) aged over thirty five. The findings of the survey supported concerns that the Care Standards Act (2000) was detrimental to the recruitment and retention of care staff, imposing what was seen as 'over-onerous' regulation. Over half of the schemes reported difficulties in recruiting and approximately 40% had difficulty in retaining carers over the twelve months prior to the survey. However, the study did not expand on any reasons for this and gave 'potential' reasons only. The study also relied on the filling out and returning of questionnaires, and reported that the response rate varied for different sections of the questionnaire. The type of support options within the schemes surveyed also varied. For example, some schemes provided services for older adults, some for adults with mental health problems and some with added physical disabilities. The range of service provision was also wide, providing not only registered long-term care, but also a variety of support and respite services. It could be hypothesised that different issues would arise for the recruitment and retention of staff who provide support to these different groups of people.

One further study that was slightly different to those outlined above, looked at older family carers, service users and individuals who provided short term Adult Family Placements for the carers. This study looked at family placements for adults with learning disabilities who were living with older family of origin carers (McConkey *et al.*, 2004). The focus of this study was more in depth and explored the experiences of Adult Family Placements, including the benefits of such schemes. Twenty-five family carers aged fifty-five and over, of people

with learning disabilities, using one of two placement schemes in Northern Ireland, were studied. In total, thirty people provided Adult Family Placements for service users aged between twenty-four and seventy-five. Service users gave a number of reasons for liking their placements. The most common were that the Adult Family 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 to those in their own home. All family of origin carers reported finding the schemes helpful, but the main theme that arose was that it gave them a break from caring (44%), and 36% of family of origin carers specifically mentioned that it was a break for both themselves and the service user. 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. Adult Family Placement providers also talked about what had lead them into their role, most common was previous experience of working in learning disabilities. Wanting to pass the time, knowing someone who provided a placement and a long standing interest in fostering were also mentioned. Similarly to other findings (Gage, 1995; Bernard, 2004) nearly all the Adult Family Placement providers were 'middle aged women', and the difficulties in recruitment, especially recruitment of males, were noted.

However, as mentioned earlier, it is important to note that this study focussed on people who provided short term Adult Family Placements for adults with learning disabilities, the motivation for which may be very different to those who provide long term or permanent placements for people. Some individuals also provided short term placements for more than one person with a learning disability at the same time; this may have meant that the experiences for them and the service users they provided placements for could be very different to another provider who only provides one placement. Therefore it may be difficult to generalise the results. As well as this, the study was relatively small and only looked at two agencies based in Northern Ireland.

1.12.1 Recruitment

The difficulty of recruiting and retaining Adult Family Placement providers is recognised as a theme throughout the literature (McConkey *et al.*, 2004; Bernard; 2004). To date, only one study has examined this in the area of Adult Family Placements. Hanrahan's (2006) study set out to examine the responses to an advertising campaign to recruit placement providers for adults with a learning disability. A retrospective examination of documented information of 49 respondents to Adult Family Placements was undertaken, supplemented with telephone contacts. Results confirmed that blanket advertising was a successful strategy for recruitment. However, the study concluded that to maximise outcomes, advertising should target experienced people and those who have reared children. An understanding of why people choose not to provide a placement may also serve as important information for future recruitment and training. However, this study did not follow up individuals who chose not to provide placements. This study also acknowledged that it did not examine the influence of partners, spouses and other family members on the decision to provide a placement which may have added a different dimension to the research. This study supports previous findings (McConkey *et al.*, 2004) where advertising that was targeted at an experienced workforce was more successful than blanket advertising. This study also recommended that current providers should be encouraged to promote their work through their social networks and to speak of the benefits they derive from it (McConkey *et al.*, 2005).

1.13 Carer Motivations

There is relatively little research on the reasons and motivations for involvement in Adult Family Placement Schemes. It could be hypothesised that insight into what factors motivate individuals to provide a placement is essential in helping to recruit and retain such individuals. British studies of these schemes have stressed that carers rarely enter such schemes purely for financial return; most have other altruistic or personal motives (e.g. Dagnan & Drewett, 1988; Dagnan, 1997; McConkey *et al.*, 2004). These studies found that service users and carers were positive about the scheme. However, few service users had severe learning disabilities and most carers had previous professional experience working with people with learning disabilities. It is important that carers find the placement rewarding and this needs to be considered as a likely predictor of the success of placements.

There appears to be only two studies in the literature which specifically look at carers' motivations for being involved in Adult Family Placement Schemes. These will now be outlined. In the first study, Dagnan (1994) looked specifically at some of the stresses, rewards and motivations associated with being a carer in an Adult Family Placement Scheme offering long-term care to adults with learning disabilities; this appears to be the only one of its kind to focus solely on these issues. Semi-structured interviews were carried out with twenty carers in an Adult Family Placement Scheme in the North of England and data concerning the burden of care was obtained from the interview with the carer. Being able to leave the client was generally considered important in providing an opportunity for carers to gain some relief from caring and to maintain social networks. The need to have a break from care was acknowledged by eighteen carers; at the time of the study there was no special provision of respite for carers of the scheme. Some carers whose children had left home reported that they felt that the service users were filling a space in their lives previously filled by their families, or, if they had retired, that had been previously filled by professional caring. These responses suggest that some of the carers accept and even welcome the burden of care. The aspects of caring reported as most stressful involved work that is considered out of the ordinary, for example, disregard for objects in the house, incontinence, and difficulties in forming relationships. Specific examples were given both of relationships where the carer felt the service user was too involved and where the carer felt that no relationship had been formed at all.

The rewards of being carers in the schemes fell into two main categories. Carers reported altruistic satisfaction from seeing service users engaging in activities and developing skills and independence that would not have been developed in their previous homes. Carers also acknowledged that being a carer fulfilled a need that they had to care. This was described both in general parental terms and in terms of more specific caring roles of parent, spouse or professional carer. There were also other more individual rewards including specific personal rewards relating to previous personal contacts with people with learning disabilities and fulfilling professional and ideological commitments to community care for people with learning disabilities. Carers reported that the service users had become quickly absorbed into the family and reported the same level of satisfaction that is more generally associated with being a member of a family or from being in a close relationship.

However, this study has a number of methodological limitations. Firstly, the study employed a small number of participants (n=20). As well as this, there appears to be some issues with the heterogeneity of the sample, which makes it difficult to compare participants' experiences; some participants were married with children at home, some were married without children at home and some were lone carers. Some participants cared for people with mild learning disabilities whilst others cared for people with severe disabilities; in addition to this, some were classed as 'not mobile' or 'incontinent'. Taking these limitations into consideration, it is suggested that any generalisation of the results should be made with caution.

The second, more recent, study was carried out by McConkey *et al.*, (2005). In this study, thirty providers of family-based placements for adults with learning disabilities in Northern Ireland were individually interviewed. All but one were female, and two thirds were aged fifty plus. The majority of providers had been recruited from the care sector, and many had experience of working with people with learning disabilities. Motivations for being involved with the scheme varied, however, by far the most common was that participants had past experience of working with people who had learning disabilities (60%). Participants reported that this gave them confidence that they could cope and would enjoy the experience. Some of the other motivations cited were wanting something to pass the time, having a friend who was a provider and having an interest in fostering. Providers were also asked what the personal gains were for their involvement and gave a number of replies. The top three replies were the 'enjoyment' 'satisfaction' and 'sense of achievement' that they got from working with people with a learning disability.

In terms of the organisation, all providers felt they were well supported, although some suggestions were made for improvements to the service. Among these were 'more breaks', 'more information' about the individual placed and publicising services 'more widely'. Nearly all of the providers had attended training and most of these had found it helpful. Finally, providers were asked what advice they would give others who were thinking about becoming involved. Just over a third of providers recommended that people were 'totally committed', and many suggested that they thought carefully about it. Having a caring nature, being patient, and having a genuine interest in people were also important qualities for providers.

However, this study is not without its limitations. It could be suggested that the participants in this study represent a somewhat biased sample. All participants were recruited via letter asking if they wanted to participate in the study, therefore it could be suggested that those who took part were more motivated to talk about their experiences because they were potentially more positive about the scheme. As well as this, providers who had left the scheme, or chose to withdraw during the selection process, were not interviewed. This could have added an important dimension to the research, and one which would seem particularly important in terms of the future recruitment and retention of Adult Family Placement providers- for example, why did they withdraw, and was there something that would have encouraged them to provide a placement? As in other studies (Gage, 1995; McConkey *et al.*, 2004), this study was based in Northern Ireland. The authors themselves recognise that generalisation of the results should be made with caution, especially as there may be different issues for different schemes around the UK. They specifically talk about the regulatory requirements for schemes which, for example, are different in England than they are in Scotland and Wales.

1.13.1 Motivations of child foster carers

Although Adult Family Placement Schemes are a somewhat unique provision of care for adults with learning disabilities, they have been compared to ‘fostering’ (NAPPS, 2004) within the literature. Similarly to carers who foster children and young people, Adult Family Placement providers are paid to provide care in their own home for an adult with a learning disability. Given that this comparison has been made, it would seem appropriate to look at the area of ‘motivations’ within the foster care literature.

Similarly to Adult Family Placement Schemes, there has been a shift from fostering as a standard caring activity, similar to every-day parenting, to one which requires regulation, supervision and training. However, at the same time foster carers are responsible for all common experiences associated with children’s lives: peer relationships, opportunities for school achievement, community activities and an ‘ordinary family setting’ (Wilson & Evetts, 2006). This appears to be similar to the guidelines set out by the government for Adult Family Placement providers which have introduced regulations and somewhat standardised the role (DoH, 2004).

Some authors comment on the hybrid nature of foster care straddling ‘family’ and ‘work’ which requires a delicate balance. It has also been suggested that a failure to treat carers as full members of the ‘team’, giving them scanty support, poor information and lack of respite, will result in the loss of this scarce resource (e.g. Kirton, 2007). This appears to be a particularly important consideration when thinking about Adult Family Placement providers, who as carers also need to strike a ‘delicate balance’ between work and family.

Researching motivations is not a new area of investigation. Jenkins (1965, cited in Nutt, 2006) investigated ninety-seven foster homes for recruitment purposes and reported that fostering fulfils unconscious and compelling needs. These were feelings of loss, a need to compensate for their own poor parenting, a desire for (more) children, and compassion for children in need. In line with this, Dando and Minty (1987) found that high standards of fostering were associated with drives based on, or derived from, strong personal needs. These studies appear to support more recent studies of the motivations of foster parents, where wanting to make a difference in a child’s life and the desire to have children in the home were important motivating factors (MacCgregor, Rodger & Cummings, 2006; Gohler & Trunzo, 2005).

Many foster families are considered to look after the children for significant periods during important years of childhood and thereby fill a parental role (Nutt, 2006). On the one hand, people who foster have a ‘parental’ role, whilst on the other they have limited capacities to make decisions about the children they look after (Sanchirico, Lau, Jablonka, & Russell, 1998). National Minimum Standards have since been introduced to regulate the profession. However, there have been many tensions and challenges regarding how the role of foster carers is conceptualised (Wilson & Evetts, 2006); this may also be an issue to consider for Adult Family Placement providers.

Nutt (2006) suggested that carers may be left ‘vulnerable’ if they are unable to maintain an emotional barrier between carer and parent status; some of the foster carers in their study seemed to identify themselves as parents whilst others identified themselves as carers, although it was not clear what factors led to this difference. Adding to this vulnerability was the fact that carers often felt emotionally attached to the children with a risk of ‘painful intensity of feeling’. Other carers found it difficult to balance the relationship because they were expected to ‘love and let go’.

Walker (2008) argued that it is important to assess the personal circumstances which have led potential substitute carers to want to care for children. Foster carers' motivations and the perceived rewards of fostering may serve to reduce the negative effects of a child's behavioural and emotional difficulties on foster carer satisfaction (Whenan, Oxlad, & Lushington, 2009). The perceived rewards of fostering, including making a difference in a child's life and seeing a child grow and develop, have been described as motivating reasons for foster carers to continue providing out-of-home care even in the face of personal or fostering challenges (Buehler, Cox & Cuddleback, 2003; Nutt, 2006). Such motivations may therefore help foster carers to maintain the relationship when the situation gets challenging. Buehler *et al.*, (2003) also found that certain characteristics were likely to inhibit successful fostering - these were non child-centred motivations, personal and impersonal inflexibility and difficulties in dealing with strong attachments to children who may have to leave.

In summary, difficulties in the foster carer-child relationship have been proposed to affect the likelihood of placement disruption (Brown & Bendar 2006). Recognition that foster parents may bring as much, if not more, to the relationship, and in turn affect placement stability, adds strength to the argument for further research exploring how the relationship is negotiated by foster carers and thus factors that may strengthen the relationship and in turn the placement. This appears to be particularly pertinent for Adult Family Placement providers, who have the responsibility of providing a stable long term placement for an individual with a learning disability.

1.13.2 Theories of motivation

As outlined above, individuals who provide Adult Family Placements and foster placements for children and young people are motivated by a number of different factors. The research suggests that there are a number of potential motivators for carers, which range from filling a space in their house to personal gains such as enjoyment, satisfaction and achievement (Dagnan, 1994; McConkey *et al.*, 2005). Such intrinsic and extrinsic types of motivation have been widely studied (Deci & Flaste, 1996; Ryan & Deci, 2000). Yet, even brief reflection suggests that motivation is hardly a unitary phenomenon. People not only vary in their level of motivation, but also in the orientation of that motivation. Orientation of

motivation concerns the underlying attitudes that give rise to the action. Motivation not only controls action being taken, but also how well it is taken.

Motivation is generally discussed in the literature in terms of intrinsic and extrinsic motivation. To be intrinsically motivated to do something, the reward gained is the actual doing of the activity itself (Ryan & Deci, 1999). According to Ryan & Deci, intrinsic motivation is linked to greater productivity, creativity, spontaneity, cognitive flexibility, and perseverance. Extrinsic motivation refers to motivation that comes from outside an individual, where the motivating factors are external rewards such as money. These rewards provide satisfaction and pleasure that the task itself may not provide (Ryan & Deci, 1999), therefore suggesting that an extrinsically motivated person will work on a task even when they have little interest in it because of the anticipated satisfaction they will get from some external reward.

Self-determination theory

In the early 1970s, when operant theory was still a relatively strong force in empirical psychology, a few investigators began to explore the concept of intrinsic motivation. Intrinsically motivated activities were defined as those that individuals find interesting and would do in the absence of operationally separable consequences. Thus, Deci (1975) proposed that intrinsically motivated behaviours are based in people's needs to feel competent and self-determined.

Self-determination Theory (SDT) (Deci & Ryan, 1985) represents a broad framework for the study of human motivation and personality. SDT articulates a meta-theory for framing motivational studies, a formal theory that defines intrinsic and varied extrinsic sources of motivation, and a description of the respective roles of intrinsic and types of extrinsic motivation in cognitive and social development and in individual differences. When people are self determined, they are believed to experience a sense of freedom to do what is interesting, personally important and vitalizing (Deci & Ryan, 2002). According to Deci & Ryan (2002), there are three psychological needs which motivate the self to initiate behavior and specify elements that are essential for psychological health and well-being of an individual. These needs are said to be universal, innate and psychological and include the need for competence, autonomy and relatedness. Competence refers to being effective in

dealing with the environment; relatedness is an individual's want to interact, connect and care for others and autonomy refers to an individual's ability to take control of their own life and make decisions though not being independent of others. The existence of these basic psychological needs and their phenomenological salience appear to yield considerable adaptive advantage at the level of individual and group selection (Ryan, Kuhl, & Deci, 1997).

No studies have directly examined specific types of motivation in relation to achievement and role success for carers within the learning disability literature. However, one study which examined individual (staff) factors associated with placement breakdown found that factors such as motivation and commitment were as important to the success of a placement as staff training (Lowe & Felce, 1995). The literature suggests that care staff provide one of the most important sources of support to people with learning disabilities and their families (Test, Flowers, Hewitt & Solow, 2004), and such support directly influences service users quality of life (Hatton, *et al.*, 1999). It would appear, that whether a person is intrinsically motivated to perform their role may be of significant importance in terms of the success and stability of the placement.

1.14 Respite

The need for family of origin carers of people with learning disabilities to have access to 'respite' breaks is well documented (Kersten, McLellan, George *et al.*, 2001). As well as long term provision, Adult Family Placements are also used for respite for individuals with a learning disability. These may take the form of day time, over night, short term or long term placements (McConkey, McConaghie, Roberts & King, 2005). It is suggested that such respite provision may be more beneficial than traditional types as it allows the maintenance of supportive relationships between carers and service users in a 'homely' environment (McNally, Ben-Shlomo & Newman, 1999).

Good short breaks have been shown to be fundamental to the health and well being of the whole family (MENCAP, 2006). However, research has shown that older people with learning disabilities are particularly ill served. Cooper (1997) found that, in Leicestershire, this group were less likely to access day care and their carers were less likely to have access to respite breaks when compared to a younger group of carers. Kersten *et al.*, (2001) noted that carers who reported unmet needs for short breaks had significantly poorer levels of

mental health and vitality compared to those who did not have this need. However, McNally, *et al.*, (1999) in a systemic review of twenty-nine studies, concluded that there was little evidence that respite breaks have either a consistent or enduring beneficial effect on the family of origin carers' well being.

It is well established in the literature that both care staff and family of origin carers of individuals with learning disabilities experience significant levels of stress (Devereux *et al.*, 2009; Mencap, 2006). The issue of respite breaks for Adult Family Placement providers offering long term care themselves would therefore appear to be an extremely important area of research. It may be suggested that, given the fact that they work and live with the service users, the potential to experience stress may be even greater than that of a typical carer or family member. It could therefore be argued that respite as a resource for Adult Family Placement providers is essential to the success of the placement in terms of the quality of life for the service users and the quality of life for the placement provider.

1.15 Conclusion

Despite the methodological limitations, the literature reviewed appears to provide empirical evidence in support of the provision of Adult Family Placement Schemes. Although there is relatively little research on Adult Family Placement Schemes within the literature, the continuation of these schemes is clearly supported by British Governments. The green paper 'Independence, Well-being and Choice' (DoH, 2005) highlights Adult Family Placements as an innovative model of social care that supports the government's vision. Adult Family placements are also in line with other key government policies, for example, 'Fulfilling the Promises' and 'Valuing People Now', (WAG, 2001; DoH, 2009).

However, more sophisticated assessment of Adult Family Placement providers has tended to be marginalised in relation to the social care workforce, especially when compared with foster carers in children's services. For example, 'Every Child Matters: the next steps' formally recognised foster carers as part of the children's workforce (DfES, 2004). But Adult Family Placement carers often fail to appear in social care workforce statistics (Gage, 1995), and fail to have the support that other social care staff may have. This is rather alarming considering that providers of adult placements undertake to provide, as near as possible, a family setting for their service user which highly resembles 'fostering' (NAAPS, 2004). The

experience of these carers has also been found to be an important factor in the success of family placement schemes (Dagnan, 1997). Although the majority of evidence in the literature suggests that Adult Family Placements provide a high quality of care (Dagnan, 1997; Bernard, 2004; McConkey *et al.*, 2005), there is the possibility that such provision could provide quite restrictive care (Dagnan, et al., 1990), which is why the continued evaluation of schemes and more focussed research in this area is necessary.

1.16 Rationale and aims of the current study

While a limited amount of research has focussed on the characteristics of providers of Adult Family Placements (Gage, 1995; McConkey *et al.*, 2005), and some research has explored the various reasons why people provide foster placements for children and young people (Nutt, 2006), very little research has looked at the reasons why people wish to become providers of Adult Family Placements (McConkey *et al.*, 2005). Identification of these factors may aid in the recruitment of Adult Family Placement providers and also inform services of training and support needs, which may have a positive impact on the retention of carers and therefore the quality of life for service users.

The current study, therefore, aims to explore in depth the experiences of individuals who provide Adult Family Placements for individuals with a learning disability. Using a qualitative methodology, the research aims to gain a detailed and rich insight into the carers' lived experiences of being placement providers. The research will explore their motivations for becoming placement providers. Although many people have experience of working with people with a learning disability (Bernard, 2004; McConkey *et al.*, 2005), the step up from this to sharing your home and life with a person with a learning disability appears to be a significant one. Therefore people's motivations and the influences behind their decision to provide a placement would seem to be an important factor to consider.

As mentioned earlier, the quality and stability of direct care staff are of fundamental importance to people with learning disabilities (Larson *et al.*, 2007). A large amount of research has focussed on paid carers and the potential for the caring role to be 'stressful' one and one that poses a risk of 'burnout' (Jenkins, Rose & Lovell, 1997; Mitchell & Hasting, 2001; Skirrow & Hatton, 2007). However, no research has looked specifically into the potential stress involved in being an Adult Family Placement provider whose role is to

provide paid, twenty four hour seven days a week care, while accepting the service user as a member of their family. It could be hypothesised that the service user is at increased risk of placement breakdown if the Adult Family Placement provider is struggling to cope due to stress or burnout. This may be especially pertinent for single carers who do not have the support of a partner.

Although some research has touched on the formation of attachments with care staff and people with learning disabilities, such exploration is still in its early stages with only one qualitative study which looks at the relationship between care staff and service users in residential support (Stimpson, 2009). Due to the type of provision they provide, Adult Family Placement providers spend far more time with the service users they support and are encouraged to treat them as 'extended family' (DoH, 2002). Therefore it would be interesting to examine whether or not issues relating to attachment form part of their experiences and impact on the care that they are able to provide.

CHAPTER TWO: METHODOLOGY

2.1 Overview of methodology

The aim of the following chapter is to provide a detailed account of how the research was developed and conducted. The design of the study will be presented, along with the background and procedure of the chosen qualitative method; the rationale for selecting this approach will also be outlined. Recruitment of participants, along with ethical considerations and a detailed description of the data collection and analysis procedures will also be discussed. This chapter also includes a description of the participants interviewed in the study.

2.2 Design

The current study used a qualitative design. The researcher carried out semi-structured interviews with participants who were providing Adult Family Placements for individuals with a learning disability (LD). The purpose of the interview was to gain a detailed and rich insight into the carers' lived experiences of being placement providers. In particular, the interview explored the influences and motivations behind their reasons for becoming placement providers. The rewards and challenges of the role and the nature of the relationships that develop between the Adult Family carer and the individual with a learning disability were also explored. Qualitative data were collected and then analysed in a manner consistent with an Interpretative Phenomenological Analysis methodology.

2.2.1 Rationale for using a qualitative design

A qualitative methodology rather than quantitative was chosen for this research. Qualitative research is concerned with how people make sense of their world and how they experience events (Willig, 2008). In qualitative studies the researcher attempts to develop understandings of the phenomena under study, based as much as possible on the perspective of those being studied (Elliot, Fischer & Rennie, 1999). This is in contrast to quantitative research which instead emphasises the importance of an objective scientific approach where the researcher

measures the relationship between variables using statistical/mathematical methods (Coolican, 2004). Researchers employing qualitative methods are interested in how an individual experiences a particular phenomenon and so the research is led by participants. This allows participants to raise topics and discuss issues that may not have been anticipated by the researcher.

The aim of the current study was to explore the experiences of individuals who provided Adult Family Placements for people with a learning disability. Therefore, a qualitative methodology was deemed appropriate as it would allow the researcher to explore participants' experiences and the meaning they attribute to these experiences. By exploring individual perspectives and experiences, qualitative research enables the facilitation of genuinely novel insights and the development of new understandings (Willig, 2008); this type of methodology can also empower participants where they feel listened to and feel that their contribution is valued (Del Busso, 2004). This is particularly important for areas where there is a paucity of existing literature (Elliot *et al.*, 1999). As discussed in chapter one, there is little research focussing specifically on the experiences of those who provide Adult Family Placement Schemes for people with a learning disability, for this reason, a qualitative methodology was considered an appropriate way of exploring this phenomenon.

2.2.2 Overview of Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a relatively new form of qualitative methodology which has become increasingly attractive as a research method within the field of psychology (Reid, Flowers & Larkin, 2005). IPA has become well established in psychological research, particularly within the UK (Smith 2004).

IPA has been informed by three theoretical traditions and is distinct from other approaches. From a phenomenological perspective IPA is concerned with the way in which individuals gain knowledge of the world around them (Willig, 2008). IPA involves exploring in detail individual personal and lived experience (Smith & Etough, 2007), attempting to understand such experiences with a focus on how people make sense of them and what meanings those experiences hold (Smith, 2004). IPA is therefore particularly well suited to exploring topics within health, social and clinical psychology where there is a need to discern how people perceive and understand significant events in their lives (Reid *et al.*, 2005). It has also been

argued that IPA methodology as opposed to other more typical quantitative methodologies may address research questions in a more meaningful way, particularly where research is concerned with complex or novel phenomena (Smith & Osborn, 2003).

At the same time, in relation to its hermeneutic or interpretative perspective, IPA appreciates that research is a dynamic process and recognises the central role that the researcher holds in making sense of personal experience (Smith, Flowers & Larkin, 2009). Smith (2004) suggests that IPA research involves a two stage interpretation process (or double hermeneutic): that is, the participant is trying to make sense of their personal and social world and in turn, the researcher attempts to make sense of the participants' perception of their world. Thus, access to the participants' experience depends on and is complicated by the researcher's own conceptions, which are required in order to make sense of that other personal world through a process of interpretative activity (Smith & Etough, 2007). As a result, the phenomenological analysis produced by the researcher is always an 'interpretation' of the experience of participants, requiring close engagement with the data in order to disentangle its meaning (Willig, 2008). Overall, IPA is a strongly idiographic mode of enquiry which is concerned with detailed analysis of a single case either as an end in itself or before moving on to analyse further cases (Smith *et al.*, 2009).

The present study set out to explore and understand the experiences and perspectives of individuals who provided Adult Family Placements for individuals with a learning disability. Therefore IPA was chosen as the methodology because of its emphasis on meaning making and lived experience. Its application to clinical practice was also an important consideration in the decision to use IPA. The intended audience of this study was primarily clinicians, practitioners and others who require an understanding of the lived experience of this particular phenomenon under study (Starks & Brown Trinidad, 2007).

However, the researcher was aware that IPA shared many of the same features of Grounded Theory, another well established qualitative methodology. For example, both aim to produce a framework that represents a person's or group's view of the world. Both proceed by systematically working through a text in order to identify themes and categories that capture the essence of the phenomenon being explored, and both use categorisation in order to achieve systematic data reduction that will form a general understanding into the fundamental

process (Grounded Theory) or essence (IPA) that characterises the phenomenon (Willig, 2004). Although these similarities are present, Grounded Theory was developed to allow the study of basic social processes and is therefore more suited to address sociological research questions (Willig, 2004). In contrast, IPA is concerned with gaining a better understanding of the quality and texture of individual experiences and was therefore a more suitable methodology for this particular study.

2.2.3 Acknowledging the researcher's position

When conducting qualitative research, the researcher plays a central role in making sense of participants' experiences (Smith, 2004) and as such is recognised as the primary investigative tool (Mays & Pope, 1996). Indeed Elliot *et al.*, (1999) cite 'owning one's perspective' as a good practice guideline for qualitative research. Therefore it is important for a researcher to explicitly outline their position in relation to the research, outlining their personal values and assumptions in order to address how these may have influenced the study. Brocki & Wearden (2006) state that the researcher's role in interpretation is vital within IPA but something that is often overlooked.

With this in mind the following section will provide an account of the researcher's background and interest in this field; provide a current statement of the researcher's position in relation to the area of research; and demonstrate the use of a research diary.

The researcher was a 31-year-old white, British female from a middle class socio-economic background. At the time of the study the researcher was training as a Clinical Psychologist on the South Wales Doctoral Programme in Clinical Psychology. Previously the researcher worked for five years as an Assistant Psychologist; four of these years were spent working within Learning Disability Services.

In addition, the researcher had personal experience of a relative with a learning disability. This relative had been supported within the family home for many years until a change of circumstances meant that this was no longer an option and other support options were required; the relative has lived in supported accommodation since this time. Although the researcher had no direct responsibility for the relative, she was mindful of some of the

challenges faced by other family members when looking for an appropriate placement for this individual.

During her four years as an Assistant Psychologist the researcher became aware of a number of support options available for adults with learning disabilities who were unable to be supported in the family home. This interest developed further when the researcher embarked on clinical training. It was during this time that the researcher became aware of a small group of carers who were involved in an Adult Family Placement Scheme which was supported by the local Learning Disability Community Support Team; the researcher did not have any previous experience of this scheme within a professional capacity. As this was a relatively new scheme the team were keen to find out what had motivated individuals to provide such placements.

The researcher's personal experience of learning disabilities, coupled with an interest of support options developed on clinical placements, led to the development of a number of questions such as: Why do individuals become involved in the scheme? How do people manage this full time role, especially within their own home? What do they find rewarding and challenging? Who supports them in this role? These questions led to the development of the current research.

Throughout the entirety of the research process the researcher engaged in reflective practice which included a reflective diary (see Appendix A), conversations with the study supervisors and also with fellow trainees who were engaged in the research process. Given the trainee's previous experience, this was considered essential in developing critical self-awareness throughout the research process and in supporting decisions that were made at different stages of this process.

2.2.4 Ensuring scientific quality and rigour within qualitative research

When conducting qualitative research, the researcher is aware of the active role played in the collecting, analysing and interpreting of the lived experiences of individuals. This process is therefore open to influence and bias. In this way the nature of qualitative research is highly subjective, not only from the perspectives of the individuals who are recounting their own

personal experiences, but also from the perspective of the researcher who takes on the role of interpreting those experiences. The increased popularity of qualitative methods in recent years has put such research under greater scrutiny (Pope & Mays, 2006), hence there is a need to evaluate the 'quality' of qualitative research. However, this needs to be carried out according to the appropriate criteria. Because IPA is a creative process, any criteria for validity will need to be flexibly as opposed to prescriptively applied (Barbour, 2007; Smith *et al.*, 2009). There are a number of guidelines outlined for use when conducting qualitative research, some of which have particular relevance in the use of IPA. Elliot *et al's* (1999) guidelines will be outlined in this study as these authors are concerned with the phenomenological- hermeneutic tradition (Willig, 2004).

Owning one's own perspective

In qualitative research, it is important for a researcher to explicitly outline their position in relation to the research, outlining their personal values and assumptions and the role that these play in their understanding of the phenomenon under study. This allows the reader to interpret the analysis and also to consider alternative interpretations (Willig, 2008). Section 2.2.3 addresses the researcher's perspectives and prior experience in relation to learning disabilities and Adult Family Placement Schemes. This section also outlines the support utilised by the researcher to ensure that a position of transparency was maintained.

Situating the Sample

The researcher should provide descriptions of the sample to enable the reader to assess the relevance and applicability of the findings. Section 2.5.5 and 2.5.6 provides the description and demographics of participants which have been anonymised to ensure confidentiality.

Grounding in examples

In order for the reader to appraise the fit between the data and the researcher's understanding of them, the researcher should provide examples of data. The process of analysis undertaken by the researcher is outlined later in this chapter (section 2.6.4). In the current study participants' quotations are provided throughout Chapter Three in support of categories and themes under discussion.

Providing credibility checks

Qualitative researchers should seek to verify the credibility of the research (e.g. themes or accounts) by referring to others. It should be noted that credibility checks may be inappropriate criteria, as qualitative research offers just one of many possible interpretations of a phenomenon, or the study of something that is changing. Qualitative researchers also believe that knowledge cannot be objective, but is always shaped by those who create it, so that 'inter-rater reliability' as a check is meaningless. In the current study the researcher met with the academic and clinical supervisors at varying points throughout the research to 'check' her interpretations and analysis. Following the initial analysis process (outlined in section 2.6.4), the researcher met with her supervisors to discuss emerging themes and her interpretations to check that these made sense in relation to the data. This process of checking the credibility of the data was also repeated following the integration of themes. There was consideration about asking the participants themselves to check the transcripts and subsequent interpretations. However, it was decided, in conjunction with the academic supervisor, that due to the various demands on the participants and the strict time frame within which this study had to be conducted, this process might have caused a significant delay

Coherence

The analyses of the data should be presented in a coherent and integrated manner e.g. the use of diagrams, narratives, figures, whilst preserving nuances on the data. The coherence and integration of the current study's results and discussion had been checked by the academic and clinical supervisor.

Accomplishing general versus specific research tasks

Qualitative researchers need to be clear about their research tasks and ensure that an appropriate range of instances (e.g. participants or situations) are studied. Therefore, if the intention is to develop a general understanding of a specific phenomenon, the data should be analysed systematically and comprehensively. The aim of the current study was to investigate the experiences of individuals who provide Adult Family Placements for people with a learning disability. Consequently, an IPA methodology was utilised which allowed for this level of analysis. The limitations of the findings beyond their original contexts will be addressed in Chapter Four.

Resonance with the reader

The researcher should present information in such a way that it allows the reader to develop an appreciation and deeper understanding of the phenomenon under study; the reader should feel that the research has increased or clarified their understanding of the phenomenon. Supervision, with both the academic and clinical supervisors and the production of draft chapters, allowed resonance to be checked.

IPA advocates many of the principles of ‘good practice’ that signify as quality markers in qualitative research (Elliot *et al.*, 1999). This has led to an increasing number of IPA studies being published (e.g. Golsworthy & Coyle, 2001; Osborn & Smith, 1998).

2.3: Ethical Considerations

2.3.1 Ethical Approval

This study was subject to a full ethical review in order to safeguard participants and to ensure that the study was ethically robust. Applications were made to the Research and Development (R & D) committees of both the host health board and the health board from which participants would be recruited and interviews conducted. The research was also submitted to the Local Research Ethics Committee (LREC) for approval. The approval letters are presented in Appendix B and C.

2.3.2 Informed consent

It is important to note that participation in this study was entirely voluntary. In line with British Psychological Society’s (BPS) Code of Ethics and Conduct (2006) all participants were given information and time to understand the nature, purpose and any anticipated consequences of the research study so that they were able to give informed consent. Both written and verbal consent was sought and obtained during the recruitment and interview stages.

Once potential participants were identified, a detailed information sheet was provided (See appendix D). Potential participants had the outline of the research presented to them at a team meeting. They were then invited to ask the researcher any questions they had either in person or via the contact details given on the information sheet (contact details for the academic supervisor and the clinical supervisor were also given). It was explained to participants that they could withdraw from the research at any time without giving any reason or risking any repercussions.

Prior to conducting any interviews the researcher re-presented and discussed the information sheet with each participant and offered an opportunity for any further questions.

All participants were deemed capable of giving informed consent to take part in the current study.

2.3.3 Confidentiality and Anonymity

Confidentiality is a key aspect of any research study, and researchers have an obligation to provide complete confidentiality regarding any information about participants acquired during the research process (Willig, 2008). Confidentiality was maintained throughout all stages of the research process. No details of any potential participants were gathered until they returned the reply slip indicating that they were interested in taking part. Only the researcher had access to this information, which was stored securely and destroyed on completion of the study.

Confidentiality was maintained throughout data collection and analysis. Once participants had provided consent to take part in the research they were given a pseudonym. This name was used on all audio-tapes and transcription documents to ensure that data remained confidential and participants remained anonymous. The researcher ensured that no identifiable information was included in the transcriptions and therefore no identifiable information appears in the study report. In this particular study participants were familiar to each other and, because of this, the researcher did not discuss any participant's involvement in the research. Care was also taken to ensure the anonymity of any persons whom the participant discussed in the interview (e.g service users or other Adult Family Placement

providers). Again, no identifiable information regarding persons alluded to during interviews was used during the data analysis.

Finally, confidentiality was ensured in the write up of the report, as any identifying information was removed and all quotations used were anonymised.

2.3.4 Other ethical issues

It is important to note that, even though suggested research guidelines were followed, each research study may present different issues to consider which need further consideration (Smith *et al.*, 2009). In the present study, the researcher acknowledged that supporting an individual with a learning disability could be stressful, and was aware that any discussion around this topic could be emotive for participants. With this in mind, the questions asked by the researcher were worded sensitively and asked appropriately, and participants were informed that they could decline to answer anything that they felt uncomfortable about. Participants were also reminded that they could ask for a break during the interview should they require one.

All participants were informed that in the event of them becoming distressed in any way, the interview would be stopped and immediate emotional support would be provided. Although the trainee was experienced in engaging with carers of individuals with a learning disability, this was in a clinical context as opposed to a research context. Therefore if any additional support had been required this would have been provided by the team leader of the Adult Family Placement Scheme. However, none of the participants became distressed during the interviews, and in fact they all indicated that they had found the interview both interesting and enjoyable.

2.4 Materials

The following section outlines the materials that were used in the current study. A description and rationale of how and why they were developed is provided.

2.4.1 Participant Information Sheet

The Participant Information Sheet (Appendix D) was designed to provide potential participants with information which would allow them to make an informed decision as to whether or not they wanted to be a part of the research study. In developing the Participation Information Sheet, the researcher followed guidance set out by the National Research and Ethics Service (NRES, 2007).

The Participation Information Sheet included a reply slip and a stamped addressed envelope was attached to allow individuals to respond if they wished to participate.

2.4.2 Consent Form

The consent form (Appendix E) was designed to enable the researcher to gain written informed consent from each participant. As above, the consent form was developed in line with guidelines outlined by NRES (2007). The consent form broke down the various aspects of the study. These were:

- Confirmation in writing that the potential participant had read and understood the information sheet about the research, that had have been given an opportunity to ask questions and had come to a decision.
- Confirmation that the potential participant understood what was involved in the research.
- Confirmation that the potential participant understood that they could withdraw from the research at any time.
- Consent to take part in the research.
- Consent for the interview to be audio-taped.
- Consent for the research findings to be presented and discussed within a written document.

- Consent for direct quotations from the interview to be used and anonymised in the written document

2.4.3 Semi-structured interviews

A full explanation for the development of the semi-structured interview schedule can be found in section 2.6. Overall, the semi-structured interview schedule was designed to explore participants' experiences of providing Adult Family Placements for individuals with a learning disability.

2.5: Participants

2.5.1 Deciding on a sample

The aim of IPA research is to provide a detailed account of people's experiences or understandings of a particular phenomenon (Smith & Osborn, 2003). IPA is strongly idiographic in nature, and each case is considered in detail before there is an attempt to conduct any analysis across cases. Typically, it is recommended that only small sample sizes are examined. It is recommended in the literature that when engaging with an IPA methodology, anything between 1 and 10 participants is acceptable (Smith, 2004; Starks & Brown Trinidad, 2007; Smith *et al.*, 2009). Thus in the present study a sample size of five was considered sufficient to gain worthwhile results using a qualitative methodology. Participants are sampled in IPA using 'purposive' sampling (Smith & Eatough, 2007). This means that participants are selected on the basis that they can grant access to the particular phenomena under study. IPA researchers set out to find a homogeneous sample for which the research in question will be meaningful. In the present study, the sample is homogeneous due to the fact that all participants were currently providing a family placement for an adult with a learning disability.

2.5.2 Participant inclusion and exclusion criteria

Initial discussions were held with the clinical supervisor in order to determine the inclusion and exclusion criteria. From these discussions the following criteria were developed.

Participants were deemed suitable for recruitment if they:

- Were currently providing a family placement for an individual with a learning disability.
- Were employed by the scheme supported by the Learning Disability Community Support Team.
- Had been providing this type of placement for a minimum of twelve months.

Participants were deemed unsuitable for recruitment if they:

- Were employed by the scheme, and waiting for an individual to be placed with them.
- Had provided a placement in the past, but not at the time of the research.
- ‘Only’ provided respite placements for adults with learning disabilities.

2.5.3 Recruitment of participants

The researcher’s clinical supervisor made initial contact with the Adult Family Placement Scheme manager who was also a member of the local Learning Disability Community Support Team. From this initial contact it was agreed that the researcher would attend an Adult Family Placement Team meeting in order to introduce herself and the topic of research. These meetings occurred once a month as part of the Adult Family Placement package of support. During this meeting, the researcher presented an outline of the research and the background to the study, as well as distributing an information sheet (discussed in section 2.4.1). The information sheet allowed potential participants to make an informed decision regarding their willingness to participate. If they decided to participate, they were asked to complete a consent form on which they provided their contact details and to return it to the researcher. To ensure that all Adult Family Placement Providers were given the opportunity to take part in the research, the information sheet was also sent in the post to each provider who had been unable to attend the meeting. The researcher was only able to contact those providers who gave their consent to take part in the research. These participants were telephoned to arrange a convenient time and location in which the interviews could take

place. This also enabled the researcher to address any queries or concerns that the participants had.

2.5.4 Description of participants

This section presents a brief description of participants. It is important to provide a description of those who participated in the study so that the reader can judge the sample (Elliott *et al.*, 1999).

From a total of eighteen suitable participants who met the specified inclusion and exclusion criteria, a total of five people participated in the study: two men and three women. The ages of the participants varied between forty-four and sixty three years. The two male participants were single carers and the three female participants were married and provided the placement with their husbands. All participants had their own children, none of whom still lived at home. Participants had been employed as Adult Family Placement Providers for between one and ten years.

In total the participants provided placements for seven service users, five males and two females; two carers provided two placements each. The age range of the service users was between nineteen and seventy three years. All service users were considered to have a mild-moderate learning disability.

All participants had previous experience of working with people with learning disabilities, and two participants provided respite care as well as a placement. One of the female participants also worked part time in addition to the Adult Family Placement role. Due to the fact that participants were selected from a relatively small group of Adult Family Placement Providers, it was not felt appropriate to provide any further individualised descriptions due to the possible risk of identification. Where participant quotes are used in Chapter Three, all names have been changed in order to protect their anonymity.

2.6 Procedure for data collection

2.6.1 Rationale for using a semi-structured interview

In general, interviewing for IPA shares the same principles associated with semi-structured interviewing. It has been argued that semi-structured interviews are the most common and possibly most stringent way for data to be collected. The central objective of IPA is to understand what personal and social experiences mean to the individuals who experience them (Shaw, 2010). Such research requires the researcher to enter the life of the participant and it is extremely important that the questions posed are open ended and non directive (Willig, 2008). Therefore, the semi-structured interview was chosen for the present study because of its applicability to the methodology (Reid, Flowers & Larkin, 2005) and because it allowed the researcher to hear the participant talk about a particular aspect of their experience (Willig, 2008).

2.6.2 Development of the semi-structured interview schedule

The purpose of developing a schedule is to facilitate a comfortable interaction with the participant which will, in turn, enable them to provide a detailed account of the experience under investigation (Smith et al., 2009) A carefully constructed interview agenda helps a researcher to think about what the interview may cover (Smith & Etough 2007) and can also go some way to ensure that the interviewer does not lose sight of the original research question (Willig, 2008). Therefore the researcher will have a general idea of the area of interest and have further ideas of questions to pursue. However, the researcher will use the questions on the interview schedule as a ‘guide’ only allowing them to probe other interesting areas that may arise (Smith & Etough 2007). This allows the researcher to maintain a genuine ‘curiosity’ in regard to participants’ experiences (Clark, 2010).

In the current study the semi-structured interview schedule was developed following a review of the literature on Adult Family Placement schemes for individuals with a learning disability, discussions with the clinical supervisor and the researcher’s own interests and curiosities. The researcher also looked at guidance set out by Smith and Osborn (2003) and Willig (2008). The interview schedule is presented in Appendix F.

2.6.3 Interview procedure

Participants were required to take part in one semi-structured interview which lasted up to an hour. All interviews were audio taped and then later transcribed and anonymised.

All interviews were arranged at convenient times and locations. In the current study all interviews were conducted in participants' homes. Participants were again reminded that they were free to withdraw their involvement in the study at any time. They were also given the opportunity to ask any further questions about the study. Participants' anonymity and the confidential nature of the interview were also reiterated.

As recommended by Smith and Eatough (2003), the researcher spent time at the beginning of the interview building rapport with the participants. The researcher had also met the participants beforehand which helped put them at ease. In the present study, the researcher spent time before the interviews familiarising herself with the schedule so that it could be used simply as a guide, allowing the researcher to concentrate fully on engaging with each participant.

At the end of the interview participants were thanked and had the opportunity to ask any further questions about the research process. Participants were also asked if they would like a summary of the final results.

2.6.4 Data Analysis

In IPA studies it is necessary to record and transcribe the entire interview. Each interview was transcribed and anonymised (Willig, 2008) in order to ensure confidentiality (an example of a transcript can be found in Appendix G). The following section outlines the process by which data are analysed following guidelines published in the literature (Smith & Osborn, 2003; Willig, 2008). The process of analysis was done by hand rather than with the use of a computer package, as the researcher felt that this approach allowed her to process the information fully and become thoroughly immersed in the data.

Stage One: Initial reading of the transcript

Following the transcription of all interviews, the first stage involves immersing oneself in the data (Smith *et al.*, 2009). This involved an iterative process of reading and re-reading the text. This allowed the researcher to become familiar with and develop an overall feel for the data. At this stage the researcher used the left hand margin of the transcript to make written comments which were unfocused and wide ranging, reflecting initial thoughts about what the researcher considered to be interesting and significant within the transcript (Willig, 2008; Smith & Osborn, 2003).

Stage Two: Identifying and labelling themes

Following this initial stage, the researcher then worked through the entire transcript again moving on to a more Interpretative level of analysis. The right hand margin was used to transform initial thoughts and ideas into emerging themes. The aim at this stage was to capture something about the 'essential quality' of what is represented in the text (Willig, 2008, p.58). It is important at this stage that a clear connection between data and themes are established (Smith *et al.*, 2009). Although there is no requirement for every part of the data to generate a theme, it is important at this stage that all data are included (Smith & Osborn, 2003). Themes that emerged remained close to what was said by the participant but were represented in a more formal psychological terminology (Willig, 2008).

Stage Three: Clustering Themes

At this stage the researcher listed the emerging themes and considered them in relation to each other (Willig, 2008). Themes that were related or connected were clustered together and labelled as master themes. These themes were checked against the original transcript to ensure there was a good fit between the data and the researcher's interpretation. To ensure a good fit, the researcher attached direct quotes from the transcript to each theme to ensure that the original meaning of the theme was not lost in the interpretation (Smith & Osborn, 2003).

Stage Four: Producing a Summary Table

At this stage the researcher produced a summary table of clustered themes, which also included keywords and relevant quotations from the transcript. The summary table served to produce a clear and systematic overview of themes (Willig, 2008). The summary table only included those themes that captured something about participants' experience of the

phenomenon under study. Therefore, some of the themes identified at the second stage of analysis were excluded at this stage.

Stage Five: Continuing with other cases

The final stage of analysis involved the researcher integrating the cases. The process described above was used for each of the remaining transcripts. Summary tables were produced for each of the participants, allowing the researcher to look across all cases for convergences and divergences in the data (Smith & Osborn, 2003). Previously analysed transcripts were then re-examined in light of any new themes. Summary tables were revised for all participants, allowing the researcher to look across the entire data. Finally, 'master themes' for all transcripts were clustered into overarching 'superordinate themes'. The data analysis was completed with the construction of a table of 'superordinate themes' and their constituent 'master themes', with a selection of quotations for illustration. At this stage the results were shared with the academic and clinical supervisors to ensure credibility and coherence within the data. In line with Elliot *et al's.*, (1999) recommendations that the findings should resonate with the reader, the researcher utilised feedback from her research supervisors.

2.6.5 Dissemination of results

Following the completion of the current study, the researcher provided a summary sheet to all participants. The summary sheet provided an outline of the study's main findings and a synopsis of the clinical and service implications. It is also anticipated that the study will be written up, alongside the academic and clinical supervisors and submitted for publication in a relevant journal. In addition, the findings will be presented in the Adult Family Placement Scheme team meeting of the local Learning Disability Community Support Team.

CHAPTER THREE: RESULTS

3.1 Synopsis

This chapter provides an overview of the themes that emerged from the data. The results of the Interpretative phenomenological analysis are structured into five superordinate themes, each with their corresponding master themes. These themes are summarised in Table 3.1 (below).

Table 3.1 Summary of superordinate and master themes for participants

<u>SUPERORDINATE THEMES</u>	<u>MASTER THEMES</u>
Motivations to provide a placement	<ul style="list-style-type: none"> • Previous experience/employment • Difficult experiences • Capacity
Notion of family	<ul style="list-style-type: none"> • Being ‘one of’ the family • Impact on family members • Quality of life <p><i>-For Service Users</i> <i>-For Participants</i></p>
Scope of the role	<ul style="list-style-type: none"> • Perception • Constancy/size of role • Expectation versus reality
Emotional investment	<ul style="list-style-type: none"> • Relationships • Placement break down • Impact on personal life • Coping strategies
Personal-professional issues	<ul style="list-style-type: none"> • Rewards and benefits • Challenges and dilemmas • Personal Values • Professional sources of support • Advice for others

In the following sections, each superordinate theme and its related master themes are discussed in turn, where extensive quotes from the interviews with participants are provided throughout. Such quotes from the interviews with participants are provided throughout to allow thorough scrutiny of the analysis by the reader. Pseudonyms are used for both participants and the service users they support.

For clarity, each superordinate theme is in bold and underlined while each master theme is underlined.

3.2 Motivations to provide a placement

As this superordinate theme suggests there were particular motivations behind participants' decisions to provide Adult Family Placements. The researcher considered that this theme was an important contribution in understanding participants' experiences, and is discussed first as a way of setting the scene for the rest of the results.

3.2.1 Previous experience

In discussing their motivations behind providing Adult Family Placements, most participants talked about their previous experience or involvement in learning disabilities or a caring role, and most were able to recall a specific time in their lives when they were motivated to decide to become a placement provider.

Bill explained that his personal experience of 'providing care for people' had motivated him to seek employment in this area:

"..I wanted to work in the caring profession because I felt I just gelled to it. So I volunteered with the friends of the disabled and we took children on holidays ...then went and worked with the [name of organisation] then, so I started there with challenging behaviour and absolutely loved every moment of it." Bill.

Sue talked about developing an interest in the support needs of people with learning disabilities after working with people in her counselling role:

“ I had been counselling a young woman in work who had a learning disability, and that was really interesting...I worked quite in depth with not only her but her parents as well and I found it really interesting” Sue.

Ben was inspired after supporting people in a professional capacity to provide a similar role:

“I was managing a small team providing respite to families with disabled children...and I decided to foster myself on a respite basis” Ben.

Jan used to attend an evening club with her husband who worked with people with learning disabilities.

“my husband went into social services and two or three nights a week he worked with different people with learning difficulties, and that was about 22 years ago. There was one lady in particular that he used to pick up and we got really attached to her and some of the time I used to go with him and then he was going to this one particular club and I used to go down there with him, and you just got attached to everybody that was there. They got to know me, I got to know them...” Jan.

Out of all the participants, Fran was the only one who enquired about the role and sought relevant experience in order to be able to provide a placement.

“It wasn’t the case that you were interviewed and just went into a job you always had to have experience. So I was advised by [social worker] to go as a volunteer to the [name of company] organisation, and I used to take a young girl out and we used to go for coffee or ice cream or whatever she wanted or we used to go once a week to a group and she would join in. Then I moved to a day centre where I volunteered there for nearly two years.” Fran.

3.2.2 Difficult experiences

Some participants linked their motivation to provide the role to difficult experiences they had encountered. These experiences came from both personal and professional encounters.

Sue was working with the family of a lady who suffered a traumatic experience. She explained that this had had a huge impact on her, she felt that it could have been prevented if the lady she worked with had been supported by somebody who had acknowledged and understood her difficulties.

“...her parents were in denial and she was really at risk because she was going to night clubs and things, and then she was raped... They obviously loved their daughter, but they were so much in denial they didn't want her to have any problems, and they were putting her at risk because they were in denial” Sue.

Other participants discussed their own difficult family experiences. They felt that going through a difficult experience themselves had inspired them to make a difference in someone else's life, in order to try and prevent them experiencing the same difficulties.

“I think the main calling for me was not seeing other people suffer, because from my childhood I'd picked up on certain things and I suffered quite a lot, and not to see other people being put down or being belittled and suffer like that, which I find can still happen to people with learning disabilities.” Bill.

Bill also talked about his 'traumatic' relationship with his father, and how he could relate to others who experienced similar difficulties:

“my childhood relationship with my father was traumatic and it still is. Some of the lads I work with had similar experiences and I feel I can empathise with this”. Ben.

3.2.3 Capacity

As well as experience of a caring role or working with individuals with a learning disability, participants also talked about having the space to be able to provide a placements and being at a stage in their life where they had more time.

Fran had always stayed at home while her children lived there and talked about her enjoyment of always having a full house:

“It all started with me when my children were growing up. I stayed home with them for 20 years, and they were all starting to grow up and I knew eventually one day they’d leave home, and I’d have an empty house. I couldn’t cope with that so I wanted to work again so I found an avenue that suited me” Fran .

Sue also talked about an opportunity presenting itself, and having the space to accommodate somebody:

“At the time we had a big four bedroomed house with a huge garden and there was only me and my husband there. So when I was working with this young woman, I began to think about it and I spoke to my husband about it and he said yes...so then I got in touch and it went from there...” Sue.

In addition to this, some participants talked about their situation being one that enabled them to have more time to provide the role.

Jan had retired and commented:

“ I was working for social services with the elderly, and I finished work ... and I thought well I’ve got a bit more time now, [another carer] said, look, I’m going away, they’re looking for carers, why don’t you put your name down? And this happened like that.” Jan

Ben talked about having the opportunity since finishing work albeit for different reasons to Jan:

“...and after the second time it happened I didn’t go back to work....I felt fine in myself and now had time....so I fostered myself on a respite basis and when he was nineteen he came to live with me full time” Ben.

3.3 Notion of family

The data highlighted the ‘notion of family’ as a key characteristic of participants’ experience of being Adult Family Placement providers. Although this theme could have been incorporated into other themes, the researcher considered this to be a significant theme in terms of the impact it had on participants so chose to present it as a superordinate theme. The ‘notion of family’ was expressed by participants in the following ways.

3.3.1 Being ‘one of’ the family

All participants regarded the service users as part of the family, rather than simply somebody they cared for or supported who lived with them. They also referred to their house as the service users home.

Ben talked about his relationship with Paul:

“I’d describe my lad as my foster son, which I think is a lot more personal, I’ve treated Paul as if he was my own” Ben.

Jan also explained that she considered her relationship with the lady she supported to be on a par with her relationship with her daughter:

“I just see her as part of the family. I suppose I’d do the same for Lillian as what I would do if she was a daughter that I had. It’s hard to describe, because as it’s adult family placement and I suppose different carers would think differently, we just see her as a daughter probably who’s got learning difficulties. She’s treated the same” Jan.

Bill explained that not only did he consider the gentleman who lived with him to be part of the family, but also felt that he was part of his wider family as well:

“It’s like an extended family as well, because not only is it Charlie myself and my son, there’s my parents and my brothers and sisters, because Charlie has come to the family weddings and stuff like that. And Charlie is always invited to my brother’s house because he’s a big football fan... and they pick up Charlie have a bit of a do in his house and I don’t go but I go and pick him up” Bill.

Fran said that although she and her husband had accepted Tom as part of the family, initially she had to encourage him to treat the house as if it was his home as he was reluctant to do this:

“Even to the extent that if my husband walked into the kitchen, he’d move away from the kettle thinking he would want it, and my husband would say no, it’s OK, I don’t want it, you make your cup of tea now this is your home as well.” Fran.

3.3.2 Impact on family members

The majority of participants indicated that providing a placement for somebody with a learning disability had had a positive impact on members of their family, particularly their children and grandchildren.

Bill and Ben talked about how providing a placement for an adult with a learning disability had impacted on their children:

“I think it’s helped him a bit as well.....you know, to be more of an adult basically...It’s sort of grounded him and helped him to look at things from a different perspective as well. Bill.

Ben also commented:

“My son is completely open to it and he’s 23 now, and I’m tied up such a lot with Paul, but he’s great and he understands what I do” Ben.

However, Ben explained that although Paul had been accepted by his son, his father had refused to accept what he did for a living and it continued to cause difficulties with his relationship with his father:

“It’s not easy for everybody. My dad won’t accept what I do. I can’t visit my dad because he says don’t bring those people here...he won’t have it”. Ben.

Participants who were grandparents tended to focus on the different relationships that had developed between the people they supported and their grandchildren. Jan talked specifically about the relationship that had developed between the lady she supports and one of her grandchildren. Jan felt that the relationship between Lillian and her grandchild was more like a sibling relationship:

“They’ve got a love/hate relationship. Arguing one minute and then they love each other the next, and you mustn’t say anything about Lillian and vice versa, and it’s just the way that they are. They’re like brother and sister”. Jan.

Jan felt that this relationship had also had a positive impact on her grandchildren:

“I think my grandchildren are richer because they’ve been brought up with [service users], and they don’t see the difference...” Jan

Fran also talked about her grandchildren and commented:

“With the babies and the family, Frank came, you know, he’s come on enormously with the children. He talks to them, and if he’s off to day service in the morning and one of them’s here, they say bye, bye Frank see you later... He likes the fact that the children acknowledge him and respond to him. They do try to get him to play football, but he doesn’t bother to do that (she says laughing)”. Fran

Sue had been an Adult Family Placement provider for ten years. She talked about how endings of placements had impacted on her family, specifically her grandchildren:

“Oh yes, and my grandchildren adored her...my youngest grandchild grew up with her and he loved her, absolutely loved her. I still send her birthday presents and cards... and last year I got this card for her from my three grandchildren, and I asked them what do you want me to put in it? and my grandson said, put I miss you and love you very much, and come home and things like that. And my other grandchildren put stuff like that as well. But what amazed me was I read it all back to them before I sent it, and he said to me, yes, but Nan, we really mean that mind” Sue

3.3.3 Quality of life.

There was a strong sense from participants that the type of support they provided had enabled them to have a positive impact on service users’ quality of life. However, one thing that was apparent to the researcher throughout the interview process was the affect that the role had on the participant’s quality of life. These are discussed separately below.

3.3.3.1 For Service Users

Fran discussed the role and the different experiences she had been able to provide as a result of this:

“He’ll come anywhere with us. He’s been to Jamaica on holiday, he’s been to Turkey, I think he’s been to Egypt, I’m not sure altogether, we’re taking him away again this year... and he loves travelling now and going on a plane” Fran.

As well as the holidays he had been able to enjoy, she also talked about the personal possessions he was now able to have:

“He’s had his holidays, he’s had his outings, he’s had new clothes, he’s got his own TV, he’s got DVDs and videos coming out his ears; and he never had anything before. I mean when he came to us, the clothes he had belonged to a different gentleman... He’s got so many things that he’s never had, and he’s 73. And he’s enjoying them...he’s got much more of a social life, and he’s got a lot more confidence” Fran.

Bill felt that the placement worked well for Charlie and stated that *'it's about us all working together'*. He placed particular emphasis on the increased independence that Charlie had been able to achieve since living with him:

"Giving people the ability to go and gain skills as well. Since Charlie has come here he goes on the bus on his own, he's doing his own breakfast in the morning...he has his own front door key" Bill.

He also talked about providing respite and how he thought this also benefited Charlie:

"And by having respite as well, people have come to stay here and Charlie's made friends with them, and now he meets them down in Tesco's and stuff. So it's broadened his life and broadened his living qualities as well." Bill.

Ben was very proud of the fact that Paul had been able to engage in local community activities:

"He was with a disabled football team, [names team], and he loved it....but now he's joining the (local) mainstream rugby team up here now" Ben.

He also said that Paul had now made friends with his group of friends:

"I take my lad everywhere with me. I take him out with the bike club, and all my friends talk to him and know him and respect him and treat him well" Ben.

Jan talked about how well Lillian had developed relationships with her neighbours:

"My neighbour next door he died two years ago, it was quite sudden really, ...Oh, she missed him terrible. She really missed him awfully because she'd be out in the garden and they'd be having a chat together and [the neighbour] always had a chat with her. They [the neighbour] used to love it because when she'd be playing the piano he could hear her, and he used to say she's been at that bloody piano again, oh, it's lovely to hear her. And she really missed him after he died." Jan.

She also added that Lillian saw the people who came to stay for respite like friends who were coming over to stay for a weekend:

“Because she knows them all, she sees them all as her friends and she looks forward to different people coming”. Jan.

3.3.3.2 For participants

The researcher was struck by the sense of pride that participants felt when discussing the different experiences they had been able to provide for the service users they supported. Participants also appeared to take great pleasure in being able to provide such opportunities. However this often appeared to have a detrimental affect on their own quality of life. Throughout the interview process, the researcher became mindful of different sacrifices that participants had made in order to perform their role:

Fran explained that although the men she supported enjoyed *‘a very active social life’*, she and her husband missed out:

“The only problem we have got is our social life. We haven’t got one” Fran.

Ben explained that he enjoyed Paul’s company, but he wasn’t able to spend time alone pursuing his own interests:

“It’s nice. But the only drawback is he’s there all the time by your side so it’s difficult then...” Ben.

Jan explained that Lillian’s social life had also become her social life:

“My social life is the Tuesday Night club. I said, it sounds sad, but that’s what suits me. We don’t go out. Very rare. If we do go out, Lillian is with us, and if we’re going to meet any friends they normally come here, we don’t go visiting often. So my social life is normally revolved around adults with learning difficulties” Jan.

Similarly Fran said that if she wanted to see her friends, they would have to come and visit her:

“I’m very fortunate that I have friends that call to the house and they’ll stay and have a few drinks with us in the evening, because they know I’m tied” Fran.

Sue commented on the lack of quality time she and her husband had spent together since doing the role:

“...in the 10 years that we’ve been doing this job, we’ve never done that, nobody’s ever gone to respite for us to go on holiday by ourselves. So we’re very tied...” Sue.

3.4 Scope of the role

During the interviews, the researcher very quickly became mindful of the sheer size of the role undertaken by each of the Adult Family Placement carers. The following points provide excellent insight into the unique role that participant’s play.

3.4.1 Perception

Participants attempted to give an explanation of how they perceived their role in relation to other roles, along with their views on how others perceived or misperceived their roles.

Although Bill had been a placement provider for some years it was clear that he found it quite difficult to define what he did:

“It’s sort of on a residential platform...but, it’s being a cook, it’s being a driver, it’s being the house cleaner, it’s about giving emotional support and physical support or that person needs to be bathed, and so it’s difficult to define what being a family placement provider is basically” Bill.

Sue also felt that the role was difficult to explain as she felt that it covered so many areas:

“I think the bottom line is we look after every area of their needs. That’s what the bottom line is. And that can be healthwise, make sure they are appropriately dressed, their safety, when we’re out make sure they don’t go on the road without you, their happiness, making sure that they integrate as much as possible” Sue.

Fran offered a different explanation and perceived her role to be similar to her own parenting role:

“I think my role has continued from motherhood too, not so much motherhood but caring-hood, because it’s with older people who need constant supervision and support” Fran.

Some participants discussed other people’s perceptions or impressions of the role, and felt that generally it was misunderstood:

Fran appeared to be shocked that other people thought she didn’t work:

“...they think I don’t work. People think I have a life of luxury. I can do what I like when I like. And they don’t realise...” Fran.

Jan said she had to liaise with the day centre and struggled because *“there were a lot of people who didn’t know”* what her role was.

She also felt that the Adult Family Placement professionals lacked an understanding of the role:

“They don’t understand what it’s like to have anybody 24/7. No matter how good they are, unless you’ve got somebody with you 24/7 you don’t understand” Jan.

Sue was amazed that so many people expressed disbelief about the fact that she provided a placement for an adult with a learning disability:

“Because a lot of people that I know have said, ‘I don’t know how you could do that’ and my sister in law is a social worker for the elderly and she said ‘Oh, I could never do it, never do it’”. Sue.

3.4.2 Constancy/ size of role

When hearing participants talk about their role, the researcher quickly became aware of its uniqueness. Perhaps most salient of all was the constancy that participants talked about with the need to always be available. Participants also alluded to having to perform many roles under the umbrella of ‘Adult Family Placement provider’:

Specifically Bill talked about the constant nature of the role, comparing his role to working in a residential home. He often felt unable to relax when he was home:

“In work [work in a residential home] it’s completely different, you strip the bed, and that’s it because you can come home, you can switch off. As soon as you walk through the door you’re back to your everyday things and you can think oh I’ll have a cup of tea now and when you’ve just finished work, but doing this it’s like doing a double shift...” Bill

Fran talked about always having to be doing something:

“It’s something every day, and it’s constant...It’s like having children. It’s constant. It doesn’t stop” Fran.

Bill also commented on all of the roles he had to perform, which he felt would not be required in any other job:

“Because what it is, you’ve got administration to do and you’ve got to do your finances as well, and if there is a problem, you can’t go to your line manager, because you haven’t got a line manager here, and you can’t go to the cook to say the food’s not very good, because

there's no cook here. It's all that, so where you've got levels of management, of staff, to help you with more policies and procedures...here you've got to know the policies and procedures without having any management to help you with that... we're not classed as a residential service, but we take the roles of each individual, but we're just one person." Bill.

When talking about the different aspects of his role Ben summed it up by saying:

"...you do it all in my team..." Ben.

All other participants referred to the constant twenty-four-hour seven days a week nature of the role:

Ben felt he had very little time to himself:

"But the only respite I get from this lad is when he's in college from 8 till 3.30. So three days a week. All the rest are 24/7" Ben.

Sue not only felt that it was a continuous role, but one that came with a huge responsibility:

"It's 24/7 for a start. If something's wrong in the middle of the night, you've got to be out of bed and do whatever. The difference between doing this and looking just after someone is like I just said, it's 24 hour hands on. Although you can have a job with responsibility, like my other job, we've also got a big responsibility with this, whereas like if you were working in Tesco, you just go and do what you've got to do, but the responsibility is somebody else's. So it's a huge responsibility as well" Sue.

3.4.3. Expectation versus reality

Participants spent time during the interview reflecting on what they thought the role would entail and what the roles actually entailed. The researcher felt that this was an important theme to include, as for most participants, their expectations of their role were quite different to the reality of it.

Sue explained that when she began providing the role, carers were given the message that it was 'just a job', but in fact for her it felt much more than a job:

“...I think that’s absolutely ridiculous, so I suppose thinking about new carers, I think in the training it would be good to get it over that it is a job, but do you know I really think that if you don’t get attached there’s something wrong” Sue.

Bill talked about the fact that he had been unaware of how Charlie’s health issues would impact on his support needs:

“I didn’t realise I’d be in the hospital so much, as well, because if I was working in residential, certain staff would take over, but if Charlie goes into hospital I’m the only one to be there on call. So that’s been not realising the extent of that, because Charlie has had to go back and forth a few times to the hospital every 3 weeks regularly... but not realising the extent that Charlie had so many medical needs, and even needed to go back and forwards to the hospital as regular as he did, so that takes a toll on you as well, thinking about it.” Bill.

Jan hadn’t realised the extent that the role would impact on her personal life:

“... it’s not realising you have to give up so much, like if you have a busy social life...we used to have a caravan, but we had to sell it because we didn’t have time to use it...” Jan.

Sue also mentioned that respite was extremely difficult to negotiate:

“I think they really need to know that you can’t get respite at the drop of a hat. I think we were led to believe, well, it was said in our initial training that it’s very important to have respite, really important, and then you get to a place where you ask for it, but you can’t get it”. Sue.

Fran was aware that she did sometimes need a break, and had thought that respite would be available for these times. However she had learnt that this was not the case:

“You’re told that respite is available...because we do need a break....but it’s difficult...there’s no guarantee that its there because things happen. I find now that I can’t and I don’t want to

deal with the stress of respite, so my answer is to take them [the two service users she supports] away with us.” Fran.

3.5 Emotional investment

When listening to participants’ experiences of being placement providers, the researcher was struck by the emotional involvement that participants had with the service users they supported. Although the emotional impact of the role was experienced differently for each individual, it was clear that none of the participants viewed what they did as simply a job. Some participants appeared to develop strong bonds with the people they supported; others found it difficult to cope with placement breakdown. Most participants found that meeting with other carers helped them cope with the demands of the role.

3.5.1 Relationship with participants

Although many participants alluded to the fact that “*carers are told, ‘well it’s a job and you shouldn’t get attached’*” (Sue), it was clear from participant’s accounts that the relationships they had developed went further than this:

It was not simply the descriptions of service users, e.g. “*like a daughter to me*” (Jan) , “*my lad*” (Ben) or “*part of the family*” (Bill, Fran & Sue), which highlighted the value that participants put on their relationships with the individuals they supported, but the way in which some participants talked about this relationship.

When listening to Jan talk about Lillian, the researcher was struck by the compassion and warmth that she felt towards her. She talked about finding it difficult to imagine not performing the role:

“I could never imagine not being with Lillian. I could never, ever, imagine this house without her, she’s part of the house, part of the family.” Jan.

She talked about the fact that she and her husband enjoyed providing the role so much, even if they were in a position where they did not need to work they would still provide a placement for Lillian, because they felt that she was such an important part of the family:

“...because we always said if we won the lottery, Lillian would still be with us, she’d still come with us, you could never do anything different”. Jan.

Sue also talked about her relationship with a previous service user placed with her, and it was clear that she had cared a great deal for her:

“... she was a character, she was fabulous, she was...she was an absolute scream...she was so funny I loved her you know...” Sue.

When Bill talked about Charlie, it was evident that although he was somewhat independent, Bill still worried about him in the same way he would worry about his own son:

“Society has changed dramatically in the past 10-15 years, people getting stabbed and beaten up and, you know, some of the youth haven’t got any respect for anybody like and each other, and so that’s always a worry when Charlie goes out. When you’re in a day centre or in residential, when you come home you shut off, but when you’re here you think, is he going to be Ok? Has he remembered to take his money? Is he all right on the bus? Is he going to be hurt out there? It’s all those things and Charlie is not in the best of health...so it’s always a worry...” Bill.

3.5.2 Placement break down

For some participants, placement breakdown or the thought of it, had had a significant impact on them emotionally. This had brought up different issues for participants.

Sue was the most experienced placement provider and this issue had appeared to have impacted on her the most. She talked about how a placement had broken down with a lady she was extremely fond of and how difficult it had been to manage her own emotions:

“With [previous service user] it really took it out of us. More so for me because I was so attached to her...and it broke down, but I, Oh God, I took it really badly because she was with me everywhere I went, you know...It absolutely broke my heart. It was terrible.” Sue.

Sue also talked about another gentleman who she had provided a placement for. The placement had broken down, but they had not realised how ill he had been when he came:

“That was an awful experience that was, because the poor man came, here, Oh, he looked as if he was dying... We were horrified. Well, I think we were a bit scared, because we thought we were going to find him dead...” Sue.

She said that this had been very difficult on her and her husband; so much so that she didn't want to discuss it. She also said that it had made them think carefully about future placements:

“Oh God. It was oh. I won't go into detail because it was so bad. So that was a very bad experience. Now if we were new carers, we might have even thought of giving up completely” Sue.

Jan talked about being '*exhausted*' by a certain person she had supported and the fact that a placement she provided was particularly stressful because of the '*challenging*' nature of the service user:

“He never wanted to be with us...he was just like a lodger...it was different with him, it ended up that he was getting in control and wanted us to go out of the house so he could stay in on his own...so after three and a half years we parted company” Jan.

Although Jan had experienced placement break down, the researcher got the impression that she had not developed the same relationship as she had with the lady she currently supported. It was clear that if this placement were to break down, it would have a significant impact on Jan emotionally:

“I could never imagine not being with Lillian. I could never, ever, imagine this house without her, she’s part of the house, part of the family.” Jan.

3.5.3 Impact on personal life

The researcher was struck by how devoted participants were to their role and the individuals they supported. Two of the participants highlighted the impact this had on them, albeit for very different reasons.

Ben said that although he enjoyed the role and that Paul was *‘nice company’*, one of the biggest problems for him was the difficulty in trying to pursue his own personal relationships; he felt that he was unable to do this:

“And if I’m in a relationship, he is there, all the time, so my partner has got to be understanding of my work, and not all companions are happy if we go out for a meal to take somebody with us, if we go to the cinema or the theatre, to have somebody, if we want to stay in and chill and watch TV, to have somebody with us all the time. And that is a big, big problem for a single carer.” Ben.

Fran talked about a recent traumatic experience she had encountered and how she had felt that she was unable to grieve because she had to continue performing a role as carer. Instead of being able to take time out and look after herself she felt she had to put on a front:

“...recently I have been through a tough time, and I’ve learnt I have to put on a happy face all the time to show that everything is ok, sometimes things aren’t perfect because you’re feeling down, you’ve got to be, but it feels like you’re not allowed to grieve, or be human and you can’t just walk away”. Fran.

3.5.4 Coping strategies

The researcher was mindful that even though participants enjoyed what they did, the role sometimes took its 'toll' (Bill) on them. Participants talked about how they managed this in terms of the support they had from other carers, and, if they were not single carers, their partners.

Jan talked about a sense of cohesiveness she felt when she met up with other carers which she thought helped her cope with the pressures of the role:

"But I like to see the rest of the carers, because it's nice that they're in the same position as what we're in. So that's what I enjoy. You feel as though you're part of a team". Jan.

Sue felt very fortunate to have a 'network' of carers who she felt were very supportive:

"I think I'm lucky now because we've got like a little network of carers. There's three of us and we can phone each other and we help each other, and [other carer] that I was talking about, if I need to go somewhere, Lillian goes down there....then I've got another carer, so we just, we support each other". Sue.

Sue also found it hard to imagine how she would cope if she didn't have her husband as a support:

"It is easy when you're both doing it, because I think it must, if you were living with, you've got to do it together otherwise it wouldn't work. It wouldn't work". Sue.

Similarly to Sue, Fran also found that both the carers and her husband were good sources of support. She said that meeting with other carers was helpful, as she felt that they were able to relate to any difficulties she was experiencing:

“...plus the fact you do meet other carers and you can have a moan and a groan if you so wish...and they can understand. Not that you have to have a moan and groan all the time, but sometimes you do...” Fran.

She also talked about the additional support she had received since her husband had finished work:

“So I’ve got that support that I can just walk out of the house and I know everything will be dealt with. He doesn’t do any of the accounts or the writing up though, I do that. I don’t let him touch my books. No. But as regards the practical support, yes. He’s good.” Fran.

3.6 Personal-professional issues

In addition to the issues raised when discussing their specific roles and relationships with the service users who were placed with them, the participants also highlighted broader personal-professional issues that they felt impacted on their work. These are outlined below.

3.6.1 Rewards and benefits

The participants reflected on a number of rewards and benefits that they felt were specific to their role. Some were personal rewards that the role brought, where others were more practical rewards that were beneficial for participants.

Jan did not consider that being paid was a reward, as she felt quite strongly that if she just did it for the money there would be other less challenging jobs she could go and do. Jan talked about the many aspects of the role that she found rewarding:

“Apart from money, because it goes further than money, because I suppose if it was just the money I could go out and do something else. It’s just some of the things that Lillian comes out with, and I like the house to feel alive...So I enjoy that part of it. I enjoy I suppose the friends that I’ve made through doing it. And I think the reward is just helping somebody...and knowing that she feels secure...so it’s nice to think that you’re helping somebody. ...and I think the rewards are Lillian coming in, never knowing what she’s going to come out with, and you just end up laughing, because sometimes I think it would be very boring without her”. Jan.

The researcher got a strong sense that Sue got a lot out the relationship that she had developed with a previous service user, and simply spending time with her was rewarding for Sue:

“She was great company. She was an absolute scream. She was so funny. I loved her, you know, she was a character.” Sue.

Fran talked about the rewards in terms of ‘satisfaction’ and ‘achievement’:

“He’s got so many things that he’s never had, and he’s 73. And he’s enjoying them, so that’s rewarding, you know? It gives us a sense of achievement because we’ve been able to, at last, give him a good life, and he enjoys himself...the fact that I’m giving the two of them a lifestyle that they can enjoy has been rewarding. As I said, I wouldn’t like to be going out to work like, these days, the jobs that are around call centres or Tesco’s or things like that. I’d rather do what I’m doing because I get a lot of satisfaction out of it” Fran.

Bill took pleasure in being able to make Charlie happy:

“The reward for me is seeing Charlie happy. As long as, because Charlie’s always got a smile on his face, and I know as long as Charlie is contented and he’s happy, something is happening right”. Bill.

He also added:

“The wages are good, and yes I don’t do it for the money, but I do need to live as well, but I just love what I do” Bill.

On a more personal level, as well as the rewards for Charlie, he also perceived the role to have contributed significantly to his own life:

“...It has built my confidence up, so I can deal with certain authorities which I wouldn’t have been able to do before, or speak up for Charlie and certainly to manage my own life better. I couldn’t take responsibility myself for many years but not only am I taking responsibility for myself but for somebody else as well now...” Bill.

Some participants also talked about the more practical rewards of the role, in terms of its flexibility and reduced pressure:

“Yes. And I enjoy doing it. Because it enables me, then, on the other side of things, to have my grandchildren for a couple of hours. So there’s swings and roundabouts”. Fran.

Others talked about being able to enjoy a lot more as a result of the role:

“I really don’t want to go back to a 9-5 job. I really don’t want that, and now we can get on the bike together, it’s all been risk assessed so we can go out. If I want to go fishing he’d love it, if we just want to chill, and he’s finding this a lot easier than 9-5 as well” Ben.

Jan found that having the person living with her (as opposed to working with her somewhere else or staying temporarily) enabled her to take a more ‘relaxed’ attitude:

“It is a bit more relaxed. Once you get to know that person I think, that you’re going to have living with you, I think it just sort of happens...because I’ve done a fair bit of respite over the years, I always saw it as a challenge because you had to get to know that person and when people are coming in to your house on respite, they’re totally different...” Jan.

3.6.2 Challenges and dilemmas

Balancing the role with their personal lives (discussed in section 3.4.3.2) presented challenges for most participants. Various carers talked about the tension in terms of being paid to perform a job, but also taking on somebody as part of the family. This raised a number of different issues for individuals.

Jan explained that although she was paid to perform a job, she felt that the money didn't help her to deal with some of the difficulties, and still struggled many years later to think of what she did as a job:

“Yes, I'm getting paid for it, the money's nice, but there's a lot of upset sometimes in the house, the house is never yours when you've got somebody living with you. I don't know. I know I'm a carer, but I just see her as part of the family ...” Jan.

Bill appeared to feel quite vulnerable on times in his role, especially as he worked alone, and felt that he didn't have the support that he would have in other roles:

“If anything does go wrong then, we're more, how can I say, at risk especially myself as I work on my own, it's difficult, you know because if you're working in residential, you've got more staff there and if something did go wrong then there's more support, but on the other hand if anything happened here, Charlie would be taken away straight away until I could sort it out..., It's everything, if Charlie has a bruise or anything like that it's all got to be documented because if anybody comes back, especially the day centre, about Charlie and they'll say why's he dressed like this? Which they haven't, I'm just saying this scenario could happen, because I know people have been pulled up within the family placement with 'why is this, why is that'” Bill.

He also felt that he was more accountable in his role, and felt that as 'part of the family' there were things that typically he wouldn't have to do, but as part of the 'job' he would:

“It’s a bit like if you have a child, you walk in a puddle and they get wet or you say he fell today blah blah blah, like, my 18-year-old son came home from rugby with a massive bruise or he went to rugby playing there’s none of that, whereas [service user] if he’s had a nose bleed or he’s been coughing, it’s all got to be documented because if he did have a chest infection, when did it start? It’s all those times, dates, and everything to be presented if anything was called into evidence” Bill.

Ben talked about the difficulty of being able to strike a balance between performing a job and making sure Paul was part of the family; it was almost as if he was worried that they were having too much fun together:

“Then I don’t know whether I’m supposed to entertain him, I know I’m supposed to teach him, and we do the housework and he can use the washing machine, and then the rest of the time I’m not sure really ...we go and knock a few golf balls about, we go and do shopping in the day time. We just sort of bumble along and enjoy life” Ben.

For Bill, it was the tension that occurred when benefits that would be available to him in a ‘job’ (e.g. support worker or residential staff) were not available to them as an Adult Family Placement provider. He felt that this put him under significant pressure:

“It is a job, but there is no feedback like if you were in a team, so you have got to be 100% right all the time, and if you’re ill there is no sick payments or even anyone to take over” Bill.

Fran also felt pressure to get things right, not only for fear of them being ‘picked up on by [team member] or the scheme’, but also because one of the gentleman she supported had regular contact with his family. She felt that sometimes this presented as an extra pressure:

“He [his father] likes him to be perfect [by this she means dressed perfectly], so we do our utmost to achieve that and then it annoys me that as perfect as I can get him, things happen in the day, so you know, his dad realises what goes on, but he still expects perfection, and sometimes that’s difficult” Fran.

3.6.3 Personal values

Participants were transparent about their own personal values which they felt enabled them to be good at their job.

One participant talked about the difficulties he experienced when a service user damaged his personal belongings, but how he had managed because he felt able to see beyond his behaviour:

“You can’t shout at him...It’s all about, I know it’s a cliché, but it’s all about valuing a person, not the behaviour. But it’s difficult sometimes. It’s difficult...” Ben.

Similarly other participants reflected on how they valued each individual as a person in their own right and tried not to think of the people they supported as ‘different’ to them:

“I like to see people with learning disabilities still living within the community because we’re all human beings, I got weaknesses like the people I look after. We’ve all got different weaknesses, some people are better than others at certain things, so we’re all the same.” Bill.

Jan spoke very passionately about her role. She talked about how she saw Lillian as an individual and tried to see beyond the label of the learning disability:

“I mean I’ve always been in care, well, nearly always... but I enjoy doing what I’m doing. I think you get a lot more back off them. They can be a bit selfish, in a lot of ways, but so can we. And I think the thing is as well, the learning disability is not a tag, because they’re all individuals. They’ve all got their own little things, you know, they’ve all got their own little ways, just like we have,” Jan.

3.6.4 Professional sources of support

The participants identified a number of sources of support that were important to them. Of particular importance, were the other Adult Family Placement providers as a network of support. They also identified the Adult Family Placement professionals and especially the training provided by them as a good system of support.

In relation to the team as a good support, Bill had felt that this had helped him resolve difficult situations:

“I suppose it’s brought different challenges which through care management and [name of person on team] I’ve always been supported as well, you know, and managed to get through those difficult times”. Bill.

Participants also described supportive relationships that they had developed with members of the Adult Family Placement team:

“[Person in team] has been absolutely fantastic. She really has you know, I just phone her...she has been really, really good and I can ring her at any time”. Sue.

Jan couldn’t find anything negative to say about the support she had received:

“But as for the scheme, I can’t say anything about it. I have always found it has been good”. Jan.

Fran also appreciated the support she had received from professionals in the team:

“As I said I’ve always dealt with [person in team] and I find her very good. I dread the day she retires” Fran.

As well as finding the Scheme to be a good source of support, participants also found the training that was provided by the Adult Family Placement Team very beneficial. The two main messages from carers were that not only were able to learn from training, but they were also able to enjoy it.

Bill was very enthusiastic about the various training events he had attended:

“I thought it was very, very good, and I’ve been on like medication courses, autism, and Aspergers and stuff like that. That was excellent. Food hygiene has been good as well, and that’s excellent.” Bill.

Jan valued the training sessions, and talked about how she was able to learn something and enjoy it at the same time:

“I go to most of the training sessions. Not because I’ve got to and I know we should, but it’s because I enjoy it. I just enjoy it because you always come out of there learning something. Always” Jan.

Sue also took a lot of pleasure from attending the training:

“The training... I love the training. Because in the training all the carers are there anyway...The training is great because there’s always something that’s of interest, and you always learn something.” Sue.

Fran said that the training was helpful in keeping her up to date with things:

“You sign a contract now that you do part of the training. So yes, I find the training is very beneficial... and as I said, it’s part and parcel of your contract now that you do the training and yes, you do need to be refreshed and things. Because you can be isolated in this job as well. So, yes, training is very advantageous.” Fran.

3.6.5 Advice for others

All participants were extremely motivated to talk about their personal experiences of providing placements. As well as talking about their individual experiences, some participants wanted to offer advice to others who were thinking of providing a placement with regard to what they felt was important in order to perform the role well.

Fran appeared to feel quite strongly about the advice she would give to other carers. Her two key messages were that people should be certain that the role is for them and she felt that experience was essential to enable people to make this decision:

“Be absolutely, positively determined that it’s what you want to do. Because some people think it’s so easy and everything will be hunky dory, but you hit problems, and it can be frustrating at times sorting things out, but be absolutely sure it’s what you want to do. And like [team member] said to me, go and have experience. Go and volunteer. That was a good suggestion because I volunteered in different areas and different disabilities with people, mild, severe, moderate, and people who go into it and they’ve only gone in that one avenue, maybe they’ve got experience, but I think they should volunteer more and because it’s not a case of just feeding, clothing and keeping an eye on them at night. There’s a lot of interaction, and I think people need to widen their scope” Fran.

Ben felt that whilst previous experience of working with people with a learning disability was essential, he also thought that there were important personal qualities that people should possess:

“It’s experience and attitude, I suppose. It’s tolerance and understanding. It’s life experience” Ben.

Jan quite simply wanted others to make sure they would be able to take pleasure from providing a placement and stated that:

“You’ve got to enjoy it to do it” Jan.

Sue gave a very strong message that a carer would need to be committed to the role; the researcher felt this was also reflected in the length of time she had been performing the role (10 years).

“You are very, very, tied doing this job. OK? And you have to be someone that don’t mind that...So we’re very tied and not all people would be happy with that. I’m just trying to think what kind of person you’ve got to be. You’ve got to definitely not mind being tied, you’ve got to be somebody that always makes time for whatever they need, because it just can’t be ignored you know... I am somebody, that if there’s something that needs to be addressed, I just address it, and I don’t know if everybody is like that. But that’s just my nature, you know”. Sue

CHAPTER FOUR: DISCUSSION

4.1: Synopsis

The aim of this final chapter is 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 further research and clinical practice. The chapter will summarise the results of the study and consider these findings in relation to the existing literature base. The clinical and service implications of the results will be discussed, followed by an outline of the study's methodological strengths and limitations. Finally, areas that warrant further research will be outlined, and the conclusions of the research presented.

4.2: Review of the results

The overall aim of this study was to explore participants' experiences of providing family placements for adults with a learning disability. The analysis of the data provided a number of rich and interesting themes and a discussion of the key findings is provided below.

The participants involved in the study described their **Motivations to provide a placement**. All participants recognised that having Previous experience/employment of working with people with a learning disability had been the major influence behind their decision to become adult family placement providers. This supports previous findings, where previous experience has been highlighted as the principle motivating factor for providing a placement (e.g. McConkey, *et al.*, 2005). Participants' previous experience, and particularly their enjoyment of working with people with learning disabilities, appeared to give them 'confidence' in their ability to undertake and enjoy the role (Mcconkey, *et al.*, 2005). Participants also described a number of Difficult experiences they had been through which had motivated them to want to 'make a difference' in the lives of other people (MacGregor, *et al.*, 2006; Beehler *et al.*, 2003). Such 'intrinsic' motives have been recognised as important factors throughout the literature (Dagnan & Drewett, 1988; Dagnan, 1997; McConkey, *et al.*, 2005). On a more practical theme, participants talked about being at a stage in their life where they had the Capacity to be able to offer a placement. For some, this related to the service user filling a space in their lives previously filled another family

member. (Dagnan, 2004; Gohelr and Trunzo, 2005), and for others about the fact that they had more time since retiring was a motivating factor (Gage, 1995; McConkey *et al.*, 2005).

The **Notion of family** for participants was a key superordinate theme to emerge from their accounts, and this comprised several master themes. Service users were fully integrated into participants' families, and were clearly treated as One of the family. Being One of the family for some participants meant that they referred to service users as their 'son', or described their relationship with them as being on a par with their relationship with their 'daughter'. Others suggested that being One of the family included being part of an 'extended family' as well (DoH, 2002). Participants were encouraged to treat the house as if it were their own home, which appeared to reinforce the fact that they were thought of as One of the family and cared about and treated in the same as anybody else in the family. This appears to be in line with Moses' (2000) study, where the care workers were thought of as surrogate family members for residents which provided them with a strong sense of being cared about. Participants also felt that providing a placement for a person with a learning disability had a positive Impact on family members. In particular, this was seen as an advantage, as they felt that their children and grandchildren had benefited from the experience, as they were more accepting of people with a learning disability. Participants talked about the opportunities they were able to offer in terms of the Quality of life that service users had. This was included under the main theme of **Notion of family** because participants felt that the type of placement offered was able to have a significant impact on the Quality of life For service users they supported. For example, participants talked about being able to provide social opportunities and opportunities for skills development. They also referred to service users being more independent and having more choice which appears to fit well with a number of core life domains central to the assessment of quality of life (Felce, 1997; Perry, Lowe & Felce, 2000). This suggests that this type of provision is able to provide excellent opportunities for maximising the quality of life for people with a learning disability, and this is in line with a general consensus that smaller more individualised options are of greater benefit than bigger institutionalised ones (McConkey, 2007). However, the opportunities relating to Quality of life For Service users appeared to be distinctly different when compared to the opportunities relating to Quality of life For Participants. In fact most participants talked about the difficulties they faced in trying to negotiate a social life or spend quality time with their partners or friends.

The theme **Scope of the role** emerged from the current study and could be a potentially significant theme for dissemination and one which provides excellent insight into the unique role of an Adult Family Placement provider. The sheer size of the role was apparent, but also participants' Perception of their role appeared to be an important issue to consider. Firstly, participants appeared to struggle when asked about their own Perception of their role. This may be because they felt that their role was all encompassing and somewhat 'difficult to define'. For example, participants alluded to the term "Adult Family Placement Provider" as being an umbrella term which has many other roles within it. This may also contribute to and reinforce other people's misperceptions of their role as simply 'looking after' someone with a learning disability. A key theme to emerge from the **Scope of the role** was the Constancy/size of role. Perhaps most salient of all was the requirement of the role that participants were always available. This had a number of implications for participants, and appeared to separate them from other paid carers within learning disability services. Participants compared their role to a 'double shift' at work, and talked about being unable to switch off from it. This appears to support other studies within the literature where the caring role as been reported as one that carers feel unable to switch off from, and more importantly staff report the belief that such care and emotional involvement is essential to their role (Moses, 2000; Stimson, 2009). Participants also explained that their Expectation versus reality of the role was quite different. Firstly that it wasn't 'just a job' and there were often other issues such as the service user's health which impacted on their role. Another issue of concern for carers was respite. Participants explained that they were led to believe that respite would be available for them whenever they needed it. However, this had not been the case and when they had requested respite it had been unavailable because other service users had taken preference. This fits with previous findings where the demands of respite could not be met with appropriate placements (McConkey, Kelly, Mannan *et al.*, 2010).

A key superordinate theme to emerge from participants' accounts was **Emotional investment**, and this included several master themes. Of importance appeared to be the type of Relationships which had developed between participants and the service users they supported. It was clear from participants' accounts that they had developed very close relationships with the individuals they supported, and talked in terms of being 'attached' to the person they supported. This appears to support Bowlby's notion of forms of attachment bonds being present and active throughout the life cycle (Bowlby, 1971). Some participants found it difficult to imagine being without the service users they supported, and others talked

about the sheer pleasure they had from their company. All participants appeared to know and engage extremely well with their service user, thus supporting the idea that a successful interactional style with service users is a result of the interpersonal relationship that develops between them. Participants in this study showed that they were clearly ‘attuned’ to the needs of the service users they supported (Reinders, 2009). The type of Relationships that participants had developed with the service users they support appeared to help service users develop skills enabling them to be self reliant, confident and able to deal with difficulties. This would suggest that they had developed a nurturing and secure ‘attachment relationship’ with the people they supported (Sable, 2007) sharing a ‘mutual closeness’ with them (Stimpson, 2009).

The results also provide evidence for the development of friendships and relationships of significance with people with learning disabilities, where it has previously been suggested that this only happens for the person with a learning disability (Pockney, 2006). The nature of the Relationships that developed also raised important issues in relation to Placement breakdown. For some participants, especially those who had developed close relationships with the service users they support, the thought of Placement breakdown was almost unbearable. Others who had experienced Placement breakdown appeared to have suffered emotionally as a result. In general, the thought of placement breakdown, or the actual breaking down of placements, stirred up substantial emotional upset, which participants found extremely difficult to deal with. It could also be suggested that the Relationships that had developed between placement providers and the service users they supported acted as a protective factor in preventing Placement breakdown. Research has suggested that when attachment relationships are nurturing and secure they promote the development of adults who are self reliant and more resilient in dealing with life’s crises (Sable, 2007). The provision of placements also appeared to have a significant Impact on personal life of carers. Although the carers raised difficulties in relation to their social life, other issues were also raised in the area of personal relationships. Participants said that they felt unable to pursue a relationship due to their commitment to the role. This could potential have a detrimental effect on the caring role. As well as this, being committed to the role sometimes meant that participants neglected their own emotions and difficulties. This had not been something that the researcher had thought about prior to the interviews. One participant spoke of how her responsibilities for the people she supported meant that she was unable to deal with a traumatic family issue.

Psychological stress is considered to be a significant problem amongst care staff working in learning disabilities (Devereux *et al.*, 2009; Skirrow & Hatton, 2007). However, apart from experiencing some ‘tension’ in trying to balance their role (see below), no participants talked about being stressed or experiencing burnout in their role. This is quite surprising given the twenty-four-hour caring role that participants provided.

There may be a number of factors which served to protect the participants in this study. All participants had developed excellent relationships with the service users placed with them, which has been described as a mitigating factor in the experience of stress (Sable, 2007; Clegg *et al.*, 2005), and they also talked about the development of appropriate Coping strategies. Appropriate coping strategies have also been found to have a positive impact on levels of stress when working with adults with learning disabilities (Hastings & Brown, 2002). The development of coping strategies would appear to be key in helping Adult Family Placement providers manage their role and some of the perceived stresses associated with it. The current study revealed that participants found their relationships with other placement providers extremely beneficial. Participants felt that other carers were an important source of support. It may be that meeting with other carers gives them a sense of cohesiveness, in the same way that support from other team members is helpful for care staff (Rose *et al.*, 2003). Those who undertook the role with assistance from a partner also valued the support that this provided. Being able to work together and share the role were highlighted as important factors. The researcher was also struck by the sense of ‘self efficacy’ possessed by participants. It appears that their confidence and belief in their ability to perform the role may have also had a positive impact on their experiences (Bandura, 1994). This appears to provide support for preliminary studies which have found a strong correlation between adaptive coping and levels of self efficacy (Cudre-Mauroux, 2010).

The research suggests that burnout typically consists of three distinct elements, emotional exhaustion, loss of a feeling of accomplishment, and negative attitudes towards service users (Maslach, 1981). Clearly (as discussed below) the Rewards and benefits of their role outweighed any challenges and dilemmas that they faced, and participants felt strongly that they were ‘accomplishing’ and ‘achieving’ something. Participants also had very positive attitudes towards service users, valuing each individual in their own right. The combination of such protective factors may explain why participants in this study were not burnt out or significantly stressed.

A final superordinate theme to emerge from participants' accounts was **Personal professional issues**, which highlighted several themes which they felt impacted on the role. The first of these were the Rewards and benefits that they gained from undertaking the role. Such benefits were the enjoyment and pleasure they had from their role, the friends they had made, being able to give service users a good life and feeling 'satisfied' by this and an increase in their own confidence. The Rewards and benefits perceived by participants in the current study supported McConkey's (2005), where the top three rewards were the enjoyment, satisfaction and sense of achievement that providers gained from their role. Participants in the current study also reflected on the 'flexible' and 'relaxed' nature of the role. When comparing it to a nine to five role they felt that they had an advantage, because they could invest time getting to know the service user and could do other things such as looking after their grandchildren during the day. The financial gain was mentioned, although participants clearly stated that they did not do the job for the money but 'need to live as well'.

Although all participants clearly had a sense of enjoyment and satisfaction from their role, they raised a number of Challenges and dilemmas that they experienced. A number of participants talked about Challenges and dilemmas in terms of the tension between being paid to care for someone while also living with that person and taking them on as one of the family. This tension is frequently mentioned within the fostering literature, and it is recognised that carers have to strike a 'balance' between being a carer and a parent (Nutt, 2006). Participants reflected on the fact that they worked alone, which meant that they were unable to share the responsibility or even the risk with other people, for example members of a team. This appeared to leave participants feeling vulnerable, feeling as if they always had to get things right in order to avoid being 'picked up on' by the scheme. Another tension was the fact that participants were encouraged to treat service users as if they were a member of their family, but were required (by regulation) to keep diaries and attend to a variety of policies regarding their care, e.g. Protection of Vulnerable Adults (POVA). Other Challenges and dilemmas focussed on the lack of support or benefits that would be available in any other job. For example, one comment was that they had to treat their role as a 'job' but did not receive any feedback on how they were doing, nor were they entitled to any sick pay if they were ill. These challenges have been highlighted as having an impact on retention of carers (Kirton, 2007).

Personal values were also identified as an important factor by participants. These included being able to value people with learning disabilities and being able to see beyond their difficulties. All participants spoke passionately about the individuals they supported; it was obvious that they thought far more of the service users than as just somebody whom they were paid to care for.

Professional sources of support were also identified by participants as key to enabling them to perform their role well. The Adult Family Placement team were seen by the participants as being approachable, helpful and supportive. There was also a general consensus that they could be contacted at any time for help and advice. Another highly valued source of support was the training offered by the Adult Family Placement team. In fact, participants were very enthusiastic about the training events, stating that they were informative, educational and enjoyable. Getting together with the other providers was also considered to be an additional benefit of the training.

Finally, participants wanted to give Advice for others who were thinking about providing a placement. The main piece of advice was for others to carefully consider the role, in order to make sure that it was what they wanted to do. Participants felt that they were very tied as a result of the role, and felt that other people would need to be totally 'committed' to it. Having experience, tolerance and understanding and enjoyment from working with people with learning disabilities was also thought to be essential. The current findings supported the findings of McConkey *et al.*, (2005), where the advice that providers emphasised most was to be totally committed to and think carefully about the role.

4.3 Theoretical implications

A number of themes have emerged from the findings of the current study, and these appear to fit well with the literature on motivation, stress and burnout and attachment theory as it is conceptualised and applied to relationships 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 an individual's 'motivation' to provide Adult Family Placements is one of considerable importance. In the current study all participants discussed the influence of intrinsic motivations on their decisions to become

Adult Family Placement providers. To be intrinsically motivated to do something, the reward gained is the actual doing of the activity itself (Ryan & Deci, 1999). This was clearly illustrated in the current study, where participants' 'natural' motivation appeared to allow them to not only enjoy their role but perform extremely well at it. It has also been highlighted that such intrinsic motivation allows a person to grow in knowledge and skills and that such growth may be as important to role success as training (Ryan & Deci, 1999; Lowe & Felce, 1995).

Of particular importance and relevance to the literature is the fact that participants in the current study did not report burn-out or any significant levels of stress. However, the issue of stress and burnout in the learning disability literature has attracted and continues to attract particular attention because of the huge impact that it has been found to have on care staff. It is therefore important to consider why the participants did not report being stressed. The emerging themes highlight some potential reasons for this. Participants appeared to have a strong belief in their ability to perform the role coupled with well developed coping strategies. Potentially, the combination of these two variables meant that their experience of stress was far less than that of individuals who appraised situations as stressful and do not have the skills and abilities to cope with them.

Another contributing factor to their positive experiences may have been the type of relationship that they had developed with the service user they supported. A good relationship between a carer and a service user has been shown to be a mitigating factor in the experience of stress (Sable, 2007; Clegg *et al.*, 2005). In terms of attachment, the current findings appear to mirror other studies within the literature that suggest that secure attachment relationships are able to be developed between individuals with a learning disability and their carers. Such attachments have also been shown not only to have a positive impact on the placement experience, but the experience of caring as a whole (Sable, 2007; Stimpson, 2009). The results of the current study also support the fact that carers can also develop friendships and relationships of significance with the individuals they support (Pockney, 2006)

4.4: Clinical and service development implications

The study produced a number of themes that are important when considering the role that Adult Family Placement carers provide, and the findings raise a number of possible clinical and service development implications.

The current study provided evidence to suggest that the role of an Adult Family Placement provider within learning disability services goes far beyond that of a traditional carer or support worker. It appears that carers invest a significant amount of themselves in their role, and see their role as far more than ‘just’ a job. In addition to their many roles and responsibilities outlined in the results, the current study highlighted that Adult Family Placement carers are fundamental in meeting the psychological and emotional needs of the service users they support. Specifically, the findings show that carers appear to have embraced the ‘family’ philosophy of the provision, with service users viewed as fully integrated members of the family. Indeed the carers clearly ‘care about’ rather than simply ‘care for’ the service users they support. Participants’ accounts of their experiences highlight the value they placed on the relationships, and indeed support the notion that people with learning disabilities and carers are able to develop effective attachment relationships (e.g. Stimpson, 2009; Schuengel, 2010).

Although the participants in this study appeared to be well trained and felt adequately supported by other carers and Adult Family Placement Team professionals, they appeared to have received very little preparation and training in relation to the management of their role, relationships with service users, and the intense emotions that can arise as a result. This sometimes meant that participants’ own needs were put aside in order to tend to the needs of the service users. On the one hand, this is extremely positive, and suggestive of the high quality of care participants provide. However, it appears to leave them ‘vulnerable’ to psychological stress which would hugely impact on the quality of care they are able to provide. Therefore raising awareness of stress and the emotional impact of the role should be the responsibility of the organisation.

A potential intervention which would attempt to protect providers from the above issues would be increased support and advice from professionals involved with the team. This could be offered in a number of ways. Firstly participants could be provided with supervision. This would also be in line with policy guidance from ‘valuing people’ which stated the need for all staff, among other things to be ‘well supervised’ (DoH, 2001).

Although participants appear to be well supported, and able to contact the team at any time, they do not appear to be supervised in the same way that direct care staff are. For example, day service and residential staff all receive formal supervision from their line managers. Such supervision serves to provide a helpful space for staff to reflect on their role, and enable them to think about their own needs and how they manage them in relation to this. Supervision could be provided by a social worker or other professional linked to the team. Such support would encourage placement providers to discuss any issues of concern and prevent them feeling that they had to 'put on a happy face'. This more formal avenue of support might also be useful in preventing difficult issues arising. Previous research has highlighted that care staff's 'morale' and overall job satisfaction was closely related to the level of supervision received (Mascha, 2007).

The second way to protect carers from potential stress would be to enhance the current programme of training offered. Education and training tends to be focussed on issues relating to the service users, and the management of their behaviours and emotions. There is a wealth of literature regarding the risk of stress and burnout for care staff working with people in learning disabilities, and potentially being educated on this would help carers to acknowledge and manage any issues should they arise. Training could also be targeted at helping carers manage their emotions and to develop strategies for helping them do so. Self management and coping techniques have been found to be beneficial to staff who work in stressful situations with people with learning disabilities (Rose *et al.*, 2003).

Finally, some participants alluded to a 'network of carers' that had developed within the scheme who provide support for each other, including respite. This appeared to work extremely well for those who were involved and served as a helpful Coping mechanism. It is suggested that a more formal 'buddy system' would have a positive impact on carers in terms of them being able to share their experiences and also the strategies that they have found helpful when dealing with any difficulties. Participants in the current study emphasised the importance of being able to meet with people who were in the same situation, as such contact enabled them to share experiences and to learn from each other.

At an organisational level, this would mean more commitment from services to ensure regular supervision for placement providers. The Adult Family Placement scheme has already committed to mandatory training for providers, but it is suggested that expanding this would be extremely beneficial for the providers and therefore for the scheme as a whole.

Where specific services users present with complex emotional and behavioural difficulties, training could also be designed for individual carers. This could be facilitated through network training (Jenkins & Parry, 2006), a systemic model of practice developed by clinical psychologists in learning disability services, which brings the entire support network (both personal and professional) of an individual together to develop a collaborative understanding of their difficulties and support needs.

As discussed previously, regular breaks for carers are essential to ensure they can continue to provide high quality care for people with learning disabilities (McNally *et al.*, 1999; Mencap, 2006). In addition to their principle caring role, some participants also provided respite for other carers. However, the results of this study revealed that no participants were able to confidently rely on respite breaks for the service users they supported, and many did not use this service at all. Research has shown that carers who reported an unmet need for respite had significantly poorer levels of mental health and vitality (Kersten, 2001). This could have significant implications for the service users supported by these carers, especially those supported by single carers who are unable to share the burden of care.

The concerns regarding respite appear to be part of a wider organisational issue relating to the positioning of Adult Family Placement providers within the learning disability workforce. Although Adult Family Placement providers are paid to perform a role, they do not receive any of the benefits that other paid care staff would. For example, they are not entitled to sick pay, holiday pay, or any carer or compassionate leave. Furthermore, if they do want to use respite services they have to pay for it themselves (personal communication with the Adult Family Team Leader; May 19th 2011). It could be hypothesised that one of the major problems is that Adult Family Placement providers do not quite 'fit' neatly into the workforce and as a result are undervalued. They are frequently referred to as 'carers' rather than 'professionals', even though they perform many of the same tasks as care staff in residential settings. Given that the experience of these providers has been found to be an important factor in the success of the placement (Dagnan, 1997), being seen as a professional and feeling part of a wider service would seem to be of particular importance. Potentially, a change of position within the social care workforce is required, one which acknowledges Adult Family Placement providers role alongside other care staff and offers them the same rights and entitlements as other employees.

One of the master themes which arose from the current study was Advice for others. Participants felt strongly that if an opportunity arose they would welcome the chance to give advice to other people who were thinking of becoming adult family placement providers. Presently, there are no formal opportunities for current providers to speak to prospective placement providers. However, there could be an opportunity for this to happen if current providers were involved in the selection and recruitment process. This could add an important dimension to the recruitment process. Prospective providers would be able to hear first hand the experiences of other providers, and be given the opportunity to ask questions that other professionals would be unable to answer. Such a development might increase the number of people recruited to schemes. Previous research has recommended that providers promote their role and their experiences (McConkey *et al.*, 2005); it would appear that involvement in the selection process would give them an ideal opportunity.

In addition to this, there appears to be a distinct lack of involvement of service users in the selection and recruitment of new providers. A number of policy documents stress the importance of involving service users in the planning and delivering of services (DoH, 2001; WAG, 2001). Although this would require additional planning and the possible involvement of other professionals, e.g. speech and language therapists, service users would be able to make a valuable contribution to the process and such a development would bring the service in line with current Government agendas.

4.5: Methodological Strengths

4.5.1 Suitability of methodology

The overview of the literature in chapter one highlighted the lack of research into the area of Adult Family Placement Schemes for people with a learning disability, and more specifically the lack of research that provides insight into the experiences of individuals who provide such placements. A qualitative methodology was therefore 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 the participants fitted with this broad aim, and IPA is committed to the detailed exploration of personal experience (Smith, 2004). Although IPA was employed for this research, the researcher was aware that a variety of qualitative

methodologies could have been selected. IPA was chosen because it aims to explore personal experiences, therefore fitting with the aims of this study, whereas other qualitative approaches are more concerned with social processes, e.g. grounded theory (Willig, 2001).

4.5.2 Ensuring Quality

Care was taken throughout to maximise the reliability and validity of the research findings by using guidelines published by Elliot *et al.*, (1999) as outlined in chapter two. During the analysis of participants' transcripts, the researcher was mindful to keep the analysis close to the participants' accounts in the first instance, and only to move to analysis at an interpretative level later. This process was conducted to retain the centrality of the participants' voices within the study, which is fundamental to IPA (Reid *et al.*, 2005). In accordance with Elliott *et al.*, (1999), credibility checks of the analysis were conducted. The themes that emerged from the analysis were discussed with the study supervisors. This was done in order to check that the analysis remained close to what the participants actually described and also to check that the themes had validity.

There was general agreement as to the credibility of the emerging categories and themes. However, the researcher did not assume this to be evidence of reliability, as in the same way that IPA does not seek to generalise the findings, neither does it seek to confirm reliability of the findings.

IPA emphasises the role of the researcher in 'owning one's perspective', in full recognition that the entire research process may well be influenced by his or her own particular biases (Smith *et al.*, 2009). The researcher's position in relation to the research was, therefore, outlined (See Section 2.2.3); reflecting on her position throughout the research process was particularly beneficial.

4.5.3 Data collection

The researcher took additional measures to minimise the potential biases inherent in her role. For example, the researcher ensured that she sought clarification from the participants when they made ambiguous statements or assumed that the researcher had existing knowledge about issues. Also, opportunities were provided at the end of the interviews to raise any further issues that participants felt were important to discuss. Finally, consultation with

experienced clinical psychologists and other professionals involved with the Adult Family Placement Scheme was also sought throughout the various stages of this study.

IPA researchers are aware that interviews are not 'neutral' means of data collection (see Rapley, 2001). The interviewer works with the participant in flexible collaboration, to identify and interpret the relevant meanings that are used to make sense of the topic (Reid *et al.*, 2005), and there is a role for the interpretative facet of IPA in data generation as well as data analysis (Brocki & Wearden, 2006). The interview schedule was therefore developed as a 'guide' in the exploration of participants' lived experiences of providing Adult Family Placements, and a number of questions were developed in line with this broad aim. In particular, the researcher was interested in the reasons and motivations for providing placements and the rewards and challenges of supporting somebody with whom they also share their home.

In this respect, the interview schedule served a valuable purpose, as it allowed the researcher to pursue areas of interest whilst maintaining a genuine curiosity in regard to the participants experiences (Clark, 2010).

4.6 Methodological Limitations

Although a range of measures were employed to enhance the reliability and validity of the research findings, there are also a number of methodological limitations which are worthy of discussion.

The study employed a relatively small sample size of just five participants. Traditional quantitative methods, require large numbers of participants, employ inferential statistics and strive to produce findings that are generalisable to the wider population. Therefore, the question of whether the findings of the present study are useful in developing a general understanding of the experiences of Adult Family Placement provision, other than those of the current participants, is raised and this could be regarded as a limitation of the research.

However, it is widely accepted in the literature that a small sample size is often more appropriate when engaging with an IPA methodology (Smith, 2004; Starks & Brown Trinidad, 2007; Smith *et al.*, 2009), as this allows the in-depth exploration and examination

of both shared and individual experiences (Smith, 2004). The sample size was therefore considered sufficient for the current study, and although the conclusions that can be drawn from it apply to the participants in the study, generalisations to a wider population should be made with caution (Brocki & Wearden, 2006).

The recruitment methodology may have led to a biased sample given that participants were required to 'opt in' to the study. Whilst this is the most ethically sound method, it resulted in a sample of participants who were interested in discussing their experiences, which may have meant that placement providers who found the role challenging or had had a particularly difficult experience may have felt disinclined to take part in the research. This may explain why no participants reported significant levels of stress. Possibly, carers who felt they were stressed or were not coping may have opted out of taking part in the research. Participants were also recruited from a single Adult Family Placement Scheme, which presents a further bias in the sample. It is therefore not possible to state whether their experience of placement provision differs in any way from people involved in other Adult Family Placement Schemes.

Although the researcher tried to ensure the homogeneity of the sample, several aspects may have compromised this. The service users supported by the participants had very different backgrounds and experiences, different ability levels and levels of independence. Such factors may have led to differences in participants' experiences of placement provision. Also, two out of the five participants provided placements for more than one individual which may have impacted on their experiences in a way which would not have affected those providing only one placement. Similarly, out of the three who provided a single placement, two also provided respite care and their experiences with this may have also influenced the findings. There were individual differences between the placement providers in terms of age and experience of working with individuals with a learning disability which might have influenced the lens through which they viewed their experiences. However, it is recognised that the homogeneity of the sample can be constrained by issues of participant recruitment (Smith & Osborn, 2003). The researcher provided details of participant demographics for the reader to assess the extent to which such differences may have influenced the results.

The researcher therefore recognises these constraints and, consistent with the IPA approach, does not claim that the findings can be generalised beyond the current group. However, it is proposed that this research might be used as a base from which further research and understanding of the phenomena can be developed.

Unfortunately, due to time constraints, the researcher was unable to undertake credibility checks with the actual participants. This is a process whereby results are taken back to participants to establish whether the research findings accurately reflect their experiences. The researcher acknowledges the usefulness of this process in increasing the validity of the research. Therefore the credibility of the findings could be questioned, and this might be a further limitation of the study. In order to compensate for this, the researcher engaged in a process of active listening, checking her understanding throughout the interviews. In addition, the results were discussed with clinical and academic supervisors and also presented and discussed with the Adult Family Placement team manager. There were also plans in place to present the findings to the Adult Family Placement providers themselves at a later date

4.7 : Recommendations for future research

Although the researcher is aware that the current study is a relatively small and preliminary one, its findings do suggest a number of possibilities for further research.

It is recommended that this area of investigation is re-visited using different and larger sample sizes in order to further develop our understanding of the experiences of family placement providers. The study focussed on a group of participants who were selected from one Family Placement Team and were supported by professionals from the same Learning Disability Community Support Team. Therefore, as well as different and larger sample sizes, it would appear to be important to select participants from a number of different schemes throughout the UK. Such research might also help to identify whether there are other significant aspects of the experiences of providing family placements for adults with learning disabilities that have not been identified in the current study. The integration, synthesis and organisation of findings from studies examining the same phenomenon helps to present a coherent and rational description and facilitates the development of knowledge (Jensen & Onyskiw, 2003).

The current study explored the experiences of people who supported relatively able people with learning disabilities. It might therefore be useful to investigate the experiences of people providing placements for people with more severe levels of disability. It could also be informative to explore in-depth the experiences of individuals with a range of different

characteristics, such as age or gender, in order to compare and contrast experiences of the same phenomenon.

Further research is also required to investigate the experience of Adult Family Placements from the perspective of the person with the learning disability. Some research has focussed on the views of people with learning disabilities with regard to current and future accommodation (e.g. Barr, McConkey & McConachie, 2003), but this did not focus specifically on views about Adult Family Placement schemes. The current study revealed a number of perceived benefits for the service users involved in the scheme, and many providers described a closeness that had developed in their relationships. It would be interesting to explore the service user perspective in relation to these issues. The importance of research focussing on the service users' perspective is now widely acknowledged in government policies and academic literature, (DOH, 2001; Grant & Ramchara, 2007; Walmsley, 2001) and a number of studies have outlined techniques that can overcome some of the obstacles that may arise in the research process (Barr *et al.*, 2003; Gilbert, 2004; Nind, 2009). There is also an increasing interest in conducting IPA with people with learning disabilities (Lloyd, Gatherer & Kalsy, 2009).

4.8 : Conclusions

The current study has explored in-depth the experiences of individuals who provide placements within their homes for adults with a learning disability. Although previous studies have touched on some issues in relation to motivations and rewards, this appears to be the first study to provide a qualitative account focussing solely on the experiences of Adult Family Placement providers. The quality and stability of care staff are of fundamental importance to people with learning disabilities. The findings from the current study suggest that this group of 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. The findings of this study have highlighted several clinical and service implications, which primarily point to the need to provide effective supervision and support to Adult Family Placement providers, and also to enhance the programme of training offered to them. This training would serve to increase awareness of the emotional demands of the role and to assist placement providers in balancing their role effectively. Their involvement in the recruitment process is also highly recommended. Several possible directions for future research have been highlighted, and hopefully the current study has gone some way to igniting further interest in this area so that such research and development can be taken forward.

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APPENDIX A- Excerpts from reflective diary

Reflective Diary Extracts

-After gathering lots of information and doing lots of searches...there isn't that much on AFP's. Decided to contact Roy McConkey -who confirmed this. Need to link in with fostering literature as well.

-Interview 1- What a nice man. Perhaps had some expectations of a single male carer, now thinking a lot differently. Blown away by the AFP role, hadn't realised how constant it was- don't think I could do their job. Hadn't quite realised how much time they invested and how little in the way of breaks they had. Felt like a bit of a lonely role- lots of responsibility and needing to be on the ball with it. Looking forward to interviewing the others.

-Last interview done-wow-what a dedicated group of people, shame all staff weren't as committed as this. All interviewees were so welcoming and open about their experiences. My heart went out to the last lady seems to have a lot on her plate-wonder how she juggles it all really. The constancy sticks in my head and I keep thinking about the almost complete lack of social life they get-but have to remind myself of how much enjoyment they also get from their role. Quote that really stays with me was about winning the lottery and still providing a placement-fab!

-After a bit of a break I have just listened to all the interviews again and read through the transcripts; this has brought them back to life! -so much information- not sure where to start. Have begun to make notes and begin to think about themes that are coming up. Need to speak to Rosemary about them. Lots of similarities throughout the interviews.

-Writing up has been harder than I thought, especially choosing which quotes to include and which to leave out-they are all so relevant!! Need to get the first draft done and have another look I think.

APPENDIX B- Letter of Approval –R&D.



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From: Professor JI Bisson
R&D Director
R&D Office, 2nd floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

24 March 2010

Miss Leanne Joshua
South Wales Doctoral Programme In Clinical Psychology
Archway House, 77 Ty Glas Avenue
Llanishen
Cardiff
CF14 5DX

Dear Miss Joshua

Project ID : 09/MEH/4714 : Adult Family Placements For People With Learning Disabilities: The Experiences Of Families Providing These Placements.

Thank you for your recent communication regarding the above project, which was reviewed on 24 March 2010 by the Chair of the Cardiff and Vale Research Review Service (CaRRS).

Documents submitted for review were:

Document	Version no.	Date
NHS R&D form	-	-
NHS SSI form	-	-
Research proposal	1	Dec 2009
Participant Information Sheet	1	Dec 2009
Interview consent form	1	Dec2009

I am pleased to inform you that the Chair had no objection to your proposal.

You may now contact the R&D Office to obtain the sponsor signature needed for your submission to the NHS Research Ethics Committee.

R&D approval and final acceptance of sponsorship by Cardiff & Vale UHB are now subject to the following:

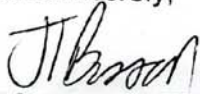
- Evidence of favourable opinion from the relevant NHS Research Ethics Committee

Once the above are in place, an R&D approval letter will be issued. You should not begin your project before receiving this written confirmation from the R&D Office.

Please ensure that you notify R&D if any changes to your protocol or study documents are required in order to obtain a favourable opinion from the Research Ethics Committee.

If you require any further information or assistance, please do not hesitate to contact the staff in the R&D Office.

Yours sincerely,



Professor Jonathan I Bisson
Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC R&D Lead Dr Jonathan Bisson

[ENCS] Obtaining a sponsorship signature - guidelines

APPENDIX C- Letter of Approval –Ethics.



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25 January 2010

Mrs Leanne Joshua
Doctoral Programme in Clinical Psyc
1st Floor, Archway House
77 Ty Glas Avenue
Llanishen
Cardiff
CF14 5DX

Dear Mrs Joshua

Study Title: Adult Family placement Schemes for people with a learning disability; the experiences of individuals providing such placements

REC reference number: 09/MMW02/63

Protocol number: 1

The Research Ethics Committee reviewed the above application at the meeting held on 20 January 2010. Thank you for attending to discuss the study.

Ethical opinion

The Committee agreed that this was a very well written proposal which should generate useful data of potential clinical utility. The Committee noted that the authorised person referred to within the application would be one of your supervisors and that the contact telephone numbers mentioned in the information sheet are work contact numbers.

It was also noted that in view of the short timescale involved and to avoid becoming overburdened, you would be content to interview between 6 – 8 participants rather than 8 – 10.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. The Committee also request that the following minor items are provided in due course:

- 1 The Committee would like to see the reference to your PhD qualification mentioned at the beginning of the information sheet under Purpose of Study.
- 2 It should be stated on the Consent Form that anonymised quotes will be used.
- 3 The Committee would like a copy of the Lone Worker Policy to be provided.
- 4 List of References to be provided
- 5 Sponsor/Indemnity details to be clarified and the sponsor declaration or letter to same effect to be provided.

Canolfan Gwasanaethau Busnes GIG Cymru,
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Abertawe. SA1 5AQ
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WHTN: 1780
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WHTN: 1780
Fax: 01792 607533
Safe Haven Fax: 01792 607234
TNT QW5/QW3 32

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

The documents reviewed at the meeting were:

Document	Version	Date
Covering Letter	1	17 December 2009
REC application	1	31 December 2009
Protocol	1	31 December 2009
Investigator CV	1	31 December 2009
Participant Information Sheet	1	31 December 2009
Participant Consent Form	1	31 December 2009
CV - Prof Frude	1	10 September 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/WMW02/63

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Mr Roy L. Evans
Chairman

Email: penny.beresford@bscs.wales.nhs.uk

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"

Copy to:

*Dr Neil Frude, Cardiff and Vale NHS Trust
[R&D office for NHS care organisation at lead site]*



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

**Adult Family placement Schemes for individuals with a learning disability:
The experiences of individuals providing such placements**

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide it is necessary for you to understand why the research is being carried out and what it would mean for you. Please take time to read the following information carefully and discuss it with others if you wish. Please do ask us if there is anything that you would like more information on or are not clear about. Please take some time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of the study is to explore the experiences of individuals who provide adult family placements for individuals with a learning disability. We would like to learn more about the rewards and potential challenges involved, and also explore some of the reasons/influences behind people's decisions to provide such placements. The study also hopes to identify any support or training needs.

Why have I been invited to participate?

As someone who provides a family placement for an adult with a learning disability, your personal experience, thoughts and opinions are extremely important to us. Your views will be very helpful to us.

Do I have to take part?

No, participation in this study is entirely voluntary and it is up to you to decide. Hopefully this information sheet will help you with your decision. If you decide to take part I will ask you to sign a consent form to show that you have agreed to take part. However, you will be free to withdraw at any time, and you do not need to give a reason for this decision. Your decision will not affect you in any way.

What does the study involve?

I am asking people who provide family placements for adults with a learning disability to participate in this study. You will be asked to take part in an interview. ***The interview will last for approximately one hour.*** I would like to hear your views and experiences of providing placements within your family for adults with learning disabilities. I would like the interview to feel as relaxed and informal as possible, so you can express your views comfortably. As far as possible, the date, time and location of the interview will be arranged at your convenience.

Will participation in this study be kept anonymous and confidential?

I will follow ethical and legal practice guidelines. All the information I receive from you will be kept ***strictly confidential and anonymous***. This means that when the results are reported, you or the individual you provide a placement for will not be identified by name. Confidentiality would however need to be broken if any disclosures of misconduct or malpractice are made during the interview, in which case I would be obliged to report these. You will also be requested to not disclose personal details of any service users you support. Similarly you will be asked not to disclose personal details of other people providing adult family placements. Interviews will be audio taped and transcribed (written up) to assist with the analysis of data. The audiotapes and transcripts will be stored in a locked cupboard and destroyed at the end of the study. Only myself as the researcher will have access to the information you provide. Any discussions with my supervisors regarding the data will be anonymous.

Are there any benefits to taking part?

By telling me your views about your experiences, thoughts and feelings of being providers of Adult Family Placements, I can begin to think about some of the rewards and challenges the job brings. I can also begin to develop an understanding of what attracts people to providing such placements. This will hopefully contribute to the support you receive as Adult Family Placement providers and reduce any potential stress. In turn, this will also help in the recruitment of new providers and improve the lives of individuals requiring family placements.

Are there any disadvantages to taking part?

It is understood that providing care and support for people with learning disabilities can be stressful at times. If you think you would find this topic too difficult to talk about then you do not have to take part. If you became upset during the interview, I would stop immediately and offer you appropriate support and suggest somebody that you could talk to.

What if there is a problem?

If you have a concern about any aspect of the study, you should speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure.

What will happen to the results of the research study?

The results will be written up and submitted in part fulfilment of my Doctoral Training in Clinical Psychology. It may also be submitted for publication in learning disability journals. Participants and others who express an interest will be sent a summary of the results of the study and its recommendations. The research will also be presented to the CST involved and at the Learning Disability Special Interest Group.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This is to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the South West Wales Ethics Committee.

This study has also been granted approval from the research and development department of Cardiff and Vale NHS Trust.

How do I take part?

If you want to get involved, please return the attached reply slip in the stamped addressed envelope. Being involved in this study is entirely voluntary. You do not have to take part if you don't want to. If you do want to get involved, I just need to know your name and contact details. I will then contact you to discuss your involvement further. If you are chosen to participate in the study, then a date, time and location that are convenient to you will be arranged. Please could you return your consent form within one month of receiving this information sheet.

For further information...

If you feel that you would like further information before deciding whether to take part in this study, please contact the researcher, who will be happy to answer any questions you may have.

CONTACT:

Leanne Joshua, Trainee Clinical Psychologist (Tel: 029 20206464);
Dr Rosemary Jenkins, Consultant Clinical Psychologist and Principle Lead Year 3/Clinical Supervisor (Tel: 029 20206464); or
Dr Neil Frude, Consultant Clinical Psychologist/ Research Director (Tel: 029 20206464)

Please keep this information sheet so that you can refer to it at any time during the course of the study.

Thank you for taking the time to read this information sheet.

APPENDIX E – Consent form



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
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Interview consent form

**Adult Family placement Schemes for Individuals with a learning Disability:
 The experiences of individuals providing such placements**

Researcher: Leanne Joshua
 South Wales Doctoral Programme in Clinical Psychology
 Archway House, 77 Ty Glas Avenue
 Llanishen, Cardiff, CF 14 5DX

		Please initial the box
1.	I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask any questions and have had these answered satisfactorily.	
2.	I understand that my participation is completely voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3.	I understand that the interview I participate in will be audio taped and transcribed. The audio tapes and transcripts will be destroyed at the completion of the study.	
4.	I understand that the research findings will be presented and discussed in a written format. I also understand that the research will be submitted in part fulfilment of the researcher's doctoral training in Clinical Psychology.	
5.	I understand that actual/direct quotations from my interview may be used in the write up of the research findings to illustrate themes. All quotes that are used in the final write up will be anonymised.	
6.	I agree to take part in the above study.	

Name of Participant:	Date:	Signature:
Name of Person taking consent:	Date:	Signature:



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Structure of interview

**Adult Family placement Schemes for Individuals with a learning Disability:
The experiences of individuals providing such placements**

Researcher: Leanne Joshua
South Wales Doctoral Programme in Clinical Psychology
Archway House, 77 Ty Glas Avenue
Llanishen, Cardiff, CF 14 5DX

Semi structured Interview schedule: Please note that due to the qualitative nature of the interview participants may direct the researcher to ask further questions. Therefore this is just a guide.

Areas of interest for the interview

- Exploration of individual's decisions about becoming an adult family placement provider; why they chose to provide this type of support.
- What influenced their decision making, any previous involvement or work with adults with a learning disability?
- What are the rewards of providing such a placement
- Any challenges/dilemmas of providing this type of placement
- How do they perceive their specific role, any similarities with other caring roles.
- Exploration of support needs of the individuals for whom they provide placements
- What support needs they have themselves
- Relationship with the team

APPENDIX G – Excerpts from a Transcript

Excerpts from a Transcript

Bill *I think the main calling for me was not seeing other people suffer, because from my childhood I'd picked up on certain things and I suffered quite a lot, and not to see other people being put down or being belittled and suffer like that, which I find can still happen to people with learning disabilities.*

Res *Did you find that that was happening when you worked in the day centre, was there something about that type of work, you thought no I want to do this full time?*

Bill *Oh definitely because you know, I like to see people with learning disabilities still living within the community because we're all human beings, I got weaknesses like the people I look after. We've all got different weaknesses, some people are better than others at certain things, so we're all*

Res *That's true*

Bill *I couldn't go out and build a wall, but somebody else can. I'm saying we've all got different qualities and dis-qualities and I suppose what I've learned through as well is active support as well. Giving people the ability to go and gain skills as well. Since Charlie has come here he goes on the bus on his own, he's doing his own breakfast in the morning and now he has his own front door key"*

Res *Brilliant.*

Bill *You know, I don't provide a hotel system, it's all about us all working together and because some people have come here for respite and they leave their plates on the table and think it's for you to clean up and I think, well, no, we're all together. I would ask my son, like I would ask you, to go and clean the table, if you've made a mess. Because me and Charlie, you know, sometimes he says you're a hard man to get on with sometimes (he laughs at this), and I say explain yourself Charlie, and he has a joke and he says well you're always asking me to mop up. And I say well you made a mess. And it's so funny, you know*

Res *It sounds like you've got a really nice relationship*

Bill *It is, it's excellent*