

**A QUALITATIVE STUDY EXPLORING THE EXPERIENCE OF
MOVING OUT OF THE FAMILY HOME
FOR AFRICAN CARIBBEAN PEOPLE WITH LEARNING DISABILITIES**

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

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ABSTRACT

The way in which people with learning disabilities experience the move out of the family home has not been extensively researched. This is surprising given the fact that Clinical Psychologists who work with people with learning disabilities are often asked to support service users, families and staff around the time of residential transition. The paucity of research is especially evident among people with learning disabilities from minority ethnic communities.

The aim of this study was to explore the experience of moving out of the family home for African Caribbean people with learning disabilities. This ethnic group appear to be overrepresented in residential services and are at greater risk of being diagnosed with mental health problems than other ethnic groups.

Six African Caribbean people with learning disabilities who had moved out of the family home were interviewed about their experiences of residential transition. The data collected from these semi-structured interviews were then analysed using Interpretative Phenomenological Analysis (Smith, 2004).

Both an individual and group analysis was carried out in order to ensure that individual voices were heard. The group analysis produced three superordinate themes. The first, 'struggle', described participants striving for empowerment and autonomy whilst feeling frustrated by their dependency and powerlessness. The second, 'connectedness', described participants' repeated experiences of loss and rejection and their desire to form close relationships and belong to a wider community. Finally the third, 'appraisal with emotion', described participants' anxieties regarding residential transitions in terms of their perceived vulnerability and limited resources as well as a sense of hope about the future.

Despite its small sample size, this study offers an insight into the experiences of a hugely under researched population. The findings can also be used to inform the clinical practice of professionals who work with such service users.

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CHAPTER ONE: LITERATURE REVIEW

1. Chapter Overview

People with learning disabilities are a disadvantaged group who have historically faced many challenges and prejudices. This review will describe the nature and causes of learning disabilities, and discuss the specific difficulties and mental health problems these people often face throughout their lives. In particular, it will examine the process of transition for people with learning disabilities, specifically the transition of leaving the family home, and place such transitions within the context of psychological theory and practice. As this study focuses on the experiences of people with learning disabilities from minority ethnic communities, the additional challenges faced by such individuals are also described throughout this review in order to provide an understanding of the specific difficulties faced by individuals who belong to more than one minority group. The literature in this chapter will be evaluated further in Chapter Four when making sense of the findings that have emerged from this study.

In order to complete this literature review, a search of the PsycINFO and PubMed databases was conducted. Search terms included combinations of words including 'learning disabilities' (and synonyms), 'ethnicity' (and synonyms), 'mental health', 'moving out', '(residential) transition', 'stress' and 'coping'. Further information was accessed from the Department of Health website and various learning disability organisations and charities. Local clinicians and lead researchers in the area of disability and ethnicity were also consulted.

2. Terminology: Disability, Ethnicity and Housing

2.1 Disability

Throughout this research, I have chosen to refer to 'people with learning disabilities' to describe the population under study, as this is the term that is most widely used by UK services and clinicians. Other terms are used across other contexts and in other countries. For example the research and academic community often favour the term 'intellectual disability', and in the US the terms 'mental retardation', 'intellectual impairment' and 'developmental disability' are often employed. Some service user led organisations in the UK such as People First prefer to use the term 'learning difficulties' but they also acknowledge that this can lead to confusion with specific learning problems such as dyslexia. They state that there is no clear consensus as to the most appropriate term but that any label should be used in a clear, inclusive and positive way (BILD, 2006). Other service user groups have echoed this message, arguing that it is the way in which a label is used that is important rather than the actual label itself (The Burton Street Group, 2006). An aim of this research is to give voice to people with learning

disabilities and it is hoped that they have been treated and talked about in a positive and respectful way throughout the research process.

2.2 Ethnicity

There is much controversy over the terms used to describe people of different ethnic origins. Historically, scientific literature classified people according to their 'race', based on a biological concept in which humans could be divided into sub species according to their visible physical characteristics. Although the definition of race has moved on and now emphasises social origins rather than biological ones, Bhopal (2004, p.442) cautions the ongoing use of the term because, 'its history is one of misuse and injustice'. Instead the term 'ethnicity' has been advocated as this more accurately describes the complexities that can contribute to ethnic origin including social grouping, culture, language, diet, religion and ancestry. Indeed Afshari & Bhopal (2002) demonstrated that the term ethnicity is gradually replacing the term race in the literature.

Although there is no consensus over terminology, this study has chosen to use the term 'minority ethnic groups/communities' to describe all ethnic communities that form a minority in the UK. This has been chosen over the term 'Black and minority ethnic' which has been criticised for inferring that Black groups do not constitute a minority ethnic group (Cole, 1993) and is therefore not a useful or valid term (Aspinall, 2002). The participants in this study all identified themselves as being 'African Caribbean'. This term has been defined as, 'a person of African ancestral origin whose family settled in the Caribbean before emigrating and who self identifies, or is identified, as African Caribbean', (Bhopal, 2004 p.443) but has also been used to describe people who have migrated directly from Africa (Agyemang, Bhopal & Bruijnzeels, 2005).

2.3 Types of Housing

Several different types of residential services/ supported accommodation are available to people with learning disabilities who move out of the family home. Various terms are used to describe such housing. These include:

- *Residential care homes/ hostels* - Relatively large homes (of up to 30 people) for people who need substantial support. Staff are typically present at all times to help out with shopping, housework, cooking, personal hygiene etc.
- *Group home* – A small flat or house in which a small group of people live. Staff visit the home to help with cooking, shopping and housework and sometimes stay overnight.

- *Living in care /living with another family/adult placement/supported lodging* – Sharing a house with the rest of a family with support provided as and when required.
- *Supported living networks/living in cluster housing/ sheltered housing*– When a group of people live near each other in the same neighbourhood, street or block of flats. Each person has their own separate house or flat but knows and meets up with others in their area regularly. Usually individuals living in this kind of accommodation predominantly care for themselves, and a support worker or keyworker helps with tasks such as accessing benefits and paying bills.

The Foundation for People with Learning Disabilities (2001)

3. Learning Disability

3.1 Definition, Prevalence and Causes

People diagnosed with a learning disability form a heterogeneous group of people, all of whom present with:

- A significant impairment of intellectual functioning, and
- A significant impairment of adaptive/ social functioning, with
- An age of onset before adulthood

(British Psychological Society, 2000)

The 2001 Department of Health White Paper, 'Valuing People', estimated that there are approximately 120,000 people with severe and profound learning disabilities, and 1.2 million people with mild/moderate learning disabilities in the UK (DoH, 2001, p15.) However, estimates of prevalence tend to differ according to the definition of learning disabilities used (Allgar et al, 2008; Whitaker & Read 2006). For example, Emerson & Hatton (2008, CEDR) estimated that there are 985,000 people in England who have a learning disability, of whom 828,000 are adults. Of this number, 177,000 were thought to be known users of learning disability services.

The causes of learning disabilities are varied, and for many are unknown. They can include prenatal factors (e.g. chromosomal disorders, genetic disorders, or maternal factors), perinatal factors (e.g. prematurity, asphyxia, intra-uterine infections, haemorrhaging, or umbilical cord accidents) and postnatal factors (e.g. infections, degenerative disorders, epilepsy and head injuries) (Sperlinger, 1997). High levels of social and material deprivation combined with poor access to maternal health care can also increase the risk of having a child with a learning disability (Emerson, Hatton, Bromley & Caine, 1998).

People with learning disabilities often have additional biological difficulties. These include physical disabilities, sensory impairments, autism spectrum disorders, epilepsy and early onset dementia. They are also at an increased risk of developing health conditions (Kappell et al, 1998), yet their healthcare is often inferior to that of the general population (Mencap, 2007; Sir Jonathon Michael: Healthcare For All, 2008).

3.2 Learning Disability and Ethnicity

According to the 2001 census, people from minority ethnic communities constitute 7.9% of the UK's population. There is however, no national data on the prevalence of learning disabilities among these communities. Local studies (e.g. Emerson et al, 1997) suggest prevalence to be up to three times greater in the Asian than in the non-Asian community. No comparable dataset exists for the African Caribbean community, although there appears to be high levels of autism in African Caribbean children with learning disabilities (CVS Consultants/Asian People with Disabilities Alliance, 1998). Emerson & Hatton (1999) predicted that by 2021, there will be a 70% increase in the number of non-White people with a learning disability, with one in ten people with a learning disability belonging to a non-White ethnic minority group.

Baxter, Poonia, Ward & Nadirshaw (1990) suggested that a higher incidence of congenital rubella may partially account for this higher prevalence rate, but that poverty may be the biggest cause. They argued that poor housing, environmental pollution, inadequate and inappropriate education, and other maternal deprivation factors such as poor diet are all likely to result in an increased vulnerability to having a child with a learning disability. In addition to this, there is a lower uptake of antenatal services and a degree of unfamiliarity with methods of genetic counselling among minority ethnic communities. Controversial suggestions that the higher frequency of consanguineous marriages in Asian communities could contribute to higher prevalence rates of learning disabilities have not been proven (Rao & Inbaraj, 1980; Terry et al, 1985; Rosenthal, Addison & Price, 1988; Pearson, 1991; Darr, 1999).

4. The Lives of People with Learning Disabilities

The majority of people with learning disabilities are cared for within the family home by relatives until carers are no longer able to support them. It is estimated that around 60% of adults with learning disabilities are living with their family, with a third of these living with a carer over the age of 70 (Mencap, 2000). Historically, the only alternative to caring for an individual with learning disabilities in the home was to place them in an institution or hospital. Such institutions were set up under the eugenic movement, led by Sir Francis Galton, which

believed that people with learning disabilities were uneducable and should be prevented from multiplying (Howard & Hendy, 2004). The conditions under which residents lived however were poor, and hospital scandals in the 1960s and 70s (DHSS 1969, 1971, 1978) exposed shocking settings and abuses. At around the same time, pressure from parental groups to give people with learning disabilities the right to an education, forced the government to pass the 1970 Education Act, which pledged that all children should receive an education regardless of their (dis)ability.

In 1971 the Department of Health White Paper 'Better Services for the Handicapped' pushed for the development of alternative, smaller-scale residences in the community for people with learning disabilities. Since this time, the large segregated institutions have been gradually replaced and all learning disability hospitals have been closed. It was hoped that this would improve the quality of life of people with learning disabilities, and increase the opportunities available to them. However despite these changes, the Department of Health acknowledged in its 2001 White Paper that people with learning disabilities are still one of the most marginalised groups in our society. Few have friends or jobs, live in their own homes, or have choice over their carers and daily activities. As a result, emphasis has been placed on the importance of promoting inclusion, choice, independence and civil rights in the lives of people with learning disabilities.

The most recent White Paper entitled 'Valuing People Now' (2007) stated that for many these goals are yet to be achieved. This was corroborated by a report compiled from national survey statistics by the Centre for Disability Research (Emerson & Hatton, 2008). This survey reported that more than four in five (83%) working age people with learning disabilities are unemployed, with even those in work receiving very low wages. Approximately 36% of people with learning disabilities are in education or training, and around 39% attend a day centre. In terms of civic involvement, only 31% of people with learning disabilities reported having voted in the most recent election, and only 28% had attended a self-advocacy meeting. Friendships with people outside of the family are rare, and 32% reported having been verbally abused by the general population as a result of their disability.

This report also described the living situations of people with learning disabilities. It estimated that approximately 70% of people with learning disabilities were living with a family member or partner, 4% were living alone, with the remainder living in some kind of supported accommodation outside of the family home. Of those in supported accommodation, the majority did not have a choice about where they lived (53%) or who they lived with (67%), but most did feel they had some privacy (65%). Statistics specific to people with learning disabilities from minority ethnic communities have not been reported.

4.1 The Lives of People with Learning Disabilities from Minority Ethnic Communities

People with learning disabilities from minority ethnic communities face what has been termed 'double discrimination' in that they are often marginalised as a result of their ethnicity and their disability (Baxter et al, 1990).

In a nationally recognised report that accompanied the Department of Health White Paper, Mir, Nocon, Ahmad & Jones (2001) reviewed the available literature on people with learning disabilities from minority ethnic communities and summarised the key issues affecting them. They reported that services for people with learning disabilities tend to be offered on a 'colour-blind' approach (Alexander, 1999), which does not distinguish between different ethnic groups. This results in service provision being geared towards the majority White culture, causing the unique needs of minority ethnic communities to be overlooked. Service providers often hold stereotypical views of minority ethnic groups which can lead to the isolation of such communities. For example, Asian families are often believed to 'look after their own' (Ahmad & Atkin, 1996) and the African Caribbean culture is often seen as 'threatening' and 'in need of control' (Ahmad & Jones, 1998; Sashidharan & Francis, 1993).

On the whole, people from minority ethnic communities were found to experience inferior levels of care compared to the White majority. For example, they are often given later diagnoses because their concerns are not heard by practitioners (Chamba, Ahmad & Jones, 1998; Baxter et al, 1990), information is sometimes withheld in order to enforce certain choices (e.g. Atkin, Ahmad & Anionwu 1998), and information is rarely available in different languages (Chamba et al, 1998; 1999). The inability to access information means that people from minority ethnic communities are often forced to depend wholly on services and professionals to meet their needs, yet the lack of cultural diversity among staff and advocates results in their specific needs not always being understood (Nadirshaw, 2000).

5. Transition for People with Learning Disabilities

Transition has been defined as, 'a sharp discontinuity with previous life events' (Brammer, 1992, p.240). Throughout their lives, people negotiate a series of transitions, in which they are forced to adapt to changes in circumstances. One such transition is the transition to adulthood, which May (2000, p.75) describes as, "an emergent status realised through the gradual acquisition of certain rights, privileges and responsibilities". The specific content of this time is often culturally determined but can involve events such as leaving school, going into education or work, learning to drive, and being legally able to vote, drink alcohol and marry. For many, it also involves leaving home. However for people with learning disabilities, this transition is often not fully realised, and for many it is postponed indefinitely.

Baker (1991) suggests some reasons why the transition to adulthood may be delayed in people with learning disabilities. He argues that typically the process of independence and separation from parents is initiated by the young person rather than the adults around them. As they grow older, children begin to form their own identity, and in doing so begin to reject the opinions and ideas of their parents. This process allows both the child and the parents to recognise their own separate identities, resulting in the child becoming more independent and assertive. It is this process of 'personal assertiveness' that people with learning disabilities find difficult to achieve, especially as they tend to have fewer peers to act as role models, and parents are reluctant to initiate this independence on behalf of the young person. In order for competence to be achieved during the process of individuation, it is important for the child to be able to experiment, to make choices about risks, and to learn from mistakes (Field, Hoffman & Posch, 1997). Again, this is not always possible for people with learning disabilities, and as a result the transition to adulthood may not be fully experienced. Shepperdson (2000) describes how parents of young people with learning disabilities face a difficult task; they are more able to control their children's lives and protect them from making mistakes, yet doing so can cause the young person to become stuck at this transitional point. Surprisingly, despite the recognition of the difficulties involved in making a successful transition to adulthood, few studies have explored the views and experiences of people with learning disabilities during such times.

5.1 Transition for People with Learning Disabilities from Minority Ethnic Communities

There is an assumption within Western culture that the transition to adulthood should involve a move towards greater independence and individuality, and that the young person should become less dependent on their family unit (Markus & Kitayama, 1991). However, this view is not always shared by people from minority ethnic communities, and therefore should not be assumed to be the aim for all people with learning disabilities. Professionals working with service users must be careful not to alienate families who value collectivism over individualism by failing to look at individuals within the context of their family environment and culture (Mir et al, 2001).

Studies have shown that South Asian families place great importance on family groups as a source of identity and support (Ahmad & Atkin 1996). Similarly, a study by Bignall & Butt (2000) showed that although African Caribbean service users valued independence, wanted to be able to have choice and control over their lives, have jobs and sometimes move away from home, they also valued being close to their families as a means of maintaining help and support.

If professionals fail to deliver a service which takes the cultural context of their service users into account, services may be mismatched, prove to be unhelpful and alienate service users and their families. Unfortunately, the paucity of research exploring the views of people with learning disabilities and their families who are from minority ethnic communities around times of transition, makes it difficult for professionals to be aware of such issues and ensure they carry out good practice.

6. Transitions, Learning Disability and Mental Health

Times of transition are commonly seen to be a particularly difficult time for most people, and are widely recognised to increase people's vulnerability to poor mental health (e.g. Schulenberg, Sameroff & Cicchetti, 2004; Strohstein, McDonough, Monette, & Shao, 2004; Thomas, Benzeval & Stansfeld, 2007).

It is only in the last 20 years that professionals have acknowledged that people with learning disabilities suffer from mental health problems and need access to mental health services (Borthwick-Duffy, 1994). In fact, epidemiological studies show that they have an increased risk of poor mental health (Whitaker & Read, 2006). Gravestock, Flynn & Hemmings (2006, p9.) argue that this is due to 'the complex interaction of often multiple biological, psychological, social and family factors'. Examples of these include communication difficulties, experiences of repeated loss, rejections or failures, vulnerability to exploitation and abuse, low self-esteem, failure to acquire social, recreational and interpersonal skills, poor coping strategies and adverse life events.

People with learning disabilities can express their psychological distress in various ways. For example, it is estimated that at any one time, approximately 15-20% of people with learning disabilities will display at least one kind of challenging behaviour (Kiernan & Qureshi, 1993). Such behaviour can represent signs or symptoms of psychological distress although it is not necessarily indicative of underlying mental health problems (Vanstraelen, Holt & Bouras, 2003). Challenging behaviour can cover a wide variety of acts but can be defined as, 'culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or other is likely to be placed in serious jeopardy, or behaviour which is likely to limit use of, or result in the person being denied access to community facilities' (Emerson, 1995, p.3). Behaviours which are commonly identified as challenging include physical and verbal aggression, sexually abusive behaviours, self-injury, property damage and stealing (Nadirshaw, 2000). Reasons for challenging behaviour can be diverse; it can sometimes have a biological origin, but more commonly it can be conceptualised as a response to poor environment (e.g. lack of stimulation), a learned behaviour which has been reinforced, a communicative act, or a

response to an emotional trauma (Joyce, Newrick, Geer & Molloy 2005). As transitions have been shown to increase people's vulnerability to poor mental health it naturally follows that they may also increase the level of challenging behaviour demonstrated by people with learning disabilities. However, the impact of transitions on the psychological wellbeing of people with learning disabilities has not yet been explored.

6.1 Transitions, Learning Disability and Mental Health for People from Minority Ethnic Communities

Central to the definition of challenging behaviour is a cultural interpretation of it as being 'abnormal'. This of course has implications for the identification and meaning of challenging behaviour in minority ethnic communities. Even when mental health problems exist without the presence of challenging behaviour, care has to be taken by professionals to understand any difficulties in the context of the service-user and family's specific cultural background (O'Hara, 2003).

Minority ethnic communities have historically had very poor access to and provision of mental health services, and have been subjected to widespread prejudices held by health professionals (Baxter et al, 1990). For the African Caribbean population, inherent prejudices in the perception of this group as being 'dangerous' has led to a disproportionate number of African Caribbean men being diagnosed with schizophrenia in comparison to their White counterparts (King, Coker, Leavey, Hoar & Johnson-Sabine, 1994; Bhugra et al, 1997). Fernando, Ndegwa & Wilson (1998) describe how Black service users are more likely to have received antipsychotic medication, to have entered hospital via compulsory admission, to have been restrained and put in seclusion as an inpatient, and to have precipitated a call to the police for help. A recent census of mental health and learning disability inpatients reported similar statistics (Commission for Healthcare Audit and Inspection, 2007). Fernando (1998) argues that Western psychiatry has consistently portrayed Black people as 'dangerous' and 'in need of control', and for those around them to be 'at risk'. He suggests that when psychiatry incorporates stereotypes into scientific practice, they come to be seen as facts. The prevailing view that Black people are 'alien', 'undesirable' and 'disturbed', only serves to alienate them from society and make them feel angry and unwanted. This then leads to a scientific diagnosis of their behaviour as 'bizarre', 'psychotic' or 'aggressive', serving to perpetuate the cycle. Perhaps unsurprisingly, the attitudes held by Western psychiatry towards African Caribbean people has led to a widespread mistrust of traditional institutions including the mental health service within this ethnic group, causing a reluctance to seek and engage in treatment (McGoldrick, Giordano & Garcia-Preto, 2005).

McKenzie & Murray (1999) suggest that the increased prevalence of schizophrenia in African Caribbean communities could partly be due to higher levels of social stress, such as institutionalised racism and life events. However, the relationship between life events such as those involved in transition and psychological wellbeing in the African Caribbean community has not been extensively studied.

7. Psychological Models of Transition

As noted earlier, transitions are common and frequent experiences that can cause stress and increase the risk of poor mental health. Several psychological models have been put forward in order to account for the experience of transition, both on an individual and developmental level, and within the context of a family unit or system.

7.1 Model of Personal Change

In their model of personal change, Fisher & Savage (1999) describe nine different emotional states people experience as they cope with transitions:

1. Anxiety due to the awareness that events lie outside of our understanding and control
2. Happiness at the prospect of potential improvement
3. Fear of the impact change may have on our self-perception
4. Threat that the change may alter our future choices and other people's perception of us
5. Guilt about the inappropriateness of our past actions
6. Depression resulting from a lack of motivation and a sense of confusion about how we will fit into the 'new' world
7. Disillusionment as awareness grows that our values, beliefs and goals are incompatible with those of the system in which we are based
8. Hostility as previous ways of functioning are no longer successful
9. Denial whereby the individual refuses to accept change and its impact on the self

Individuals are expected to experience all nine stages in a fairly linear fashion, although stages can be traversed quickly or slowly depending on the individual's self-perception, locus of control and previous experiences. The degree to which a transition adversely affects our psychological wellbeing is mediated by factors such as education, information and support, and the degree to which we are adequately prepared for the anticipated changes. Despite the popularity of this model, and its widespread acceptance in social and occupational psychology, Fisher himself acknowledges that it has not undergone any formal empirical testing, stating only that, 'anecdotal and participant observation would imply that this is a fairly robust model'. He argues that its validity can be assumed because it is an

adaptation of the Kübler-Ross five stages of grief model. However, in recent years researchers have criticised the studies from which this grief model was developed; they have questioned the internal validity of the data analysis, and the absence of description of the sample or definitions of terms used (Copp, 1998). It has also been criticised for its inflexible unidirectional movement through the stages which has not been confirmed by clinical practice studies (Buckman, 1993).

At face value, Fisher's model does appear to be a useful way of conceptualising the emotional impact of transition. However its poor research base, alongside its failure to take into account other cultures, and its inability to place the individual's experience in the context of a family unit or social group limits its applicability to clinical practice.

7.2 Lifespan Model of Developmental Change

In this model, which draws upon an extensive range of psychological theory, Hendry & Kloep (2001) put forward a theoretical framework which describes the way in which individuals approach and respond to change, and the resulting impact change can have on the individual's development.

They argued that each individual has a certain amount and type of resources which they can draw upon when facing a task. These resources are highly interactive and dynamic, and can be lost, gained and altered throughout the life course. They vary between individuals and are drawn from a variety of sources including:

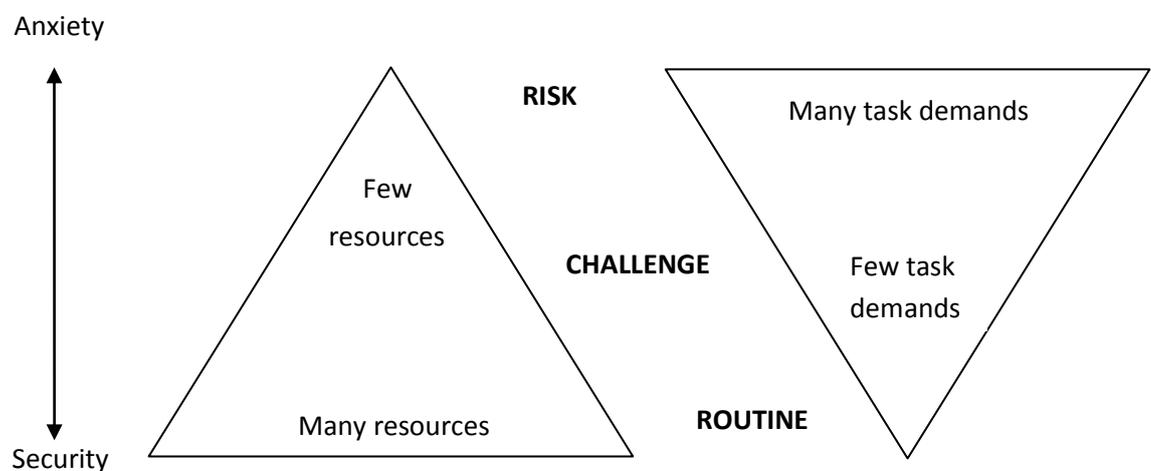
- Biological disposition (e.g. health, physical attributes, 'personality')
- Social resources (e.g. social networks and social skills)
- Skills (e.g. motor skills, literacy, appraisal, evaluation)
- Self-efficacy (i.e. self belief gained from feedback from others and experience)
- Structural resources (e.g. nationality, gender, ethnicity, social class)

According to this model, when an individual faces a task, a range of variables determine whether the resources available to the individual are sufficient to meet the task's demands, i.e. whether or not there is a 'goodness of fit'. These variables include the number and types of resources available, characteristics such as fatigue, mood and motivation, the presence of other people or tasks, and the time at which the task appears (e.g. time of day, time in lifespan, time in history). This goodness of fit can vary both between and within individuals – what is easy for one person may not be for another, and what is difficult for one person today may be easy tomorrow.

The goodness of fit determines whether a task is viewed and experienced as a routine task, a challenge, or a risk. Routine tasks are those that are less demanding and do not require much effort to overcome, allowing the individual to complete them in a state of security. Challenges are tasks that match or slightly exceed the individual's resources and so can be completed with only a small amount of anxiety. Risks are more demanding and can lead to the individual feeling highly anxious and overwhelmed (see Figure 1 below).

Figure 1: Lifespan Model of Developmental Change

Hendry & Kloep (2002, p.26)



As demonstrated in Figure 1, a state of security is experienced when an individual perceives their pool of resources to be relatively full so that they feel able to cope with the challenges of daily life comparatively easily. It is only from a position of relative security than an individual will choose to approach new challenges. In contrast, feelings of anxiety arise when the level of resources are perceived to be low in comparison with the demands of the task. When in this position, an individual will choose to avoid new challenges when possible.

When facing a task there are three possible outcomes for the individual. If the task is overcome successfully, then the process of solving it adds to the individual's pool of resources (e.g. self-efficacy may be enhanced), and development occurs. However, if a task drains an individual of their resource pool, and leaves them unable to face further challenges then decay is said to occur. Finally, when an individual only faces tasks that are always seen as routine, no new resources are added to the pool and so stagnation occurs. Stagnation can either be contented (i.e. if an individual is happy with their lifestyle and does not wish to seek out major challenges) or unhappy (i.e. when an individual does not have the resources to seek out further challenges and so is forced to avoid them). Even when stagnation is contented, it can be a risky

state as if sudden external changes occur the individual may be forced to respond without the necessary resources in place.

This concept of a 'goodness of fit' between task and resources also applies to times of transition which occur at various times throughout the lifecycle. Hendry & Kloep described such transitions as belonging to one of four categories:

1. *Maturation shifts* caused by normal biological changes and experienced in approximately the same age range by all humans in all cultures (e.g. growing teeth, puberty, menopause)
2. *Normative social shifts* which are prescribed by law and apply to all members of a particular group (e.g. starting formal education, military service, pensionable age)
3. *Quasi-normative shifts* that are expected to occur within a certain age range but which tend to be enforced by social pressure rather than law (e.g. leaving home, marriage, parenthood)
4. *Non-normative shifts* which do not occur for everyone including:
 - (a) *Off-time shifts* which happen to many people but differ in timing (e.g. teenage pregnancy)
 - (b) *Historical shifts* which happen to everyone in a particular group due to historical events (e.g. war, economic crisis)
 - (c) *Self-instigated shifts* that do not automatically happen to people and that have to be initiated by the individual and are often associated with stigma (e.g. divorce)
 - (d) *Idiosyncratic shifts* that happen to only a few people and are not predicted or expected (e.g. serious injury, winning the lottery)
 - (e) *Non-events* which form a challenge due to their absence even when they are expected

Although all transitions can induce stress, Hendry & Kloep argue that transitions that take the form of normative shifts represent less powerful challenges because individuals undergoing such transitions tend to have access to role models and sources of emotional and social support. In contrast, non-normative shifts often hit the individual unexpectedly, are not chosen or sought out, and are therefore much more challenging. They are however seen to offer more potential for personal growth and development if overcome successfully.

One of the greatest strengths of this model is that it is very well grounded in psychological theory and literature; however it has also been critiqued for drawing upon an evidence base that predominantly has its origins in Western culture. Hendry & Kloep do acknowledge that this is the case and attribute this to a lack of research from other cultures which needs to be addressed. However, they argue that as this model does not use chronological age markers for transitions, it has a structure that is flexible enough to accommodate the potentially different life trajectories across levels of (dis)ability, culture and

time. Although the particular challenges that stimulate development inevitably varies across culture and over time, 'the mechanisms of development are the same, irrespective of time and place' (2002, p.37.)

Although the model does not stipulate the particular challenges that may be faced by people who form a minority (e.g. people with learning disabilities and/or people from minority ethnic communities), it is possible to hypothesise about such groups. For example, it may be that people with learning disabilities have a more limited pool of resources with which to face challenges and thus are susceptible to a greater risk of anxiety and decay than their more able peers. It may also be the case that people with learning disabilities tend to face transitions that represent more non-normative shifts – perhaps because they are delayed (off-time) or because they do not occur at all (non-events). If this were true, people with learning disabilities may be exposed to frequent transitions which do not involve as much access to support and which therefore present more challenges, albeit challenges that present greater opportunities for personal growth. This may place them at greater risk of poor mental health as they may feel excessively anxious or overwhelmed. For people from minority ethnic communities, it may be that the transitions typically faced by certain cultures do not reflect those of the majority culture within which they are living. Again this could have an impact on their pool of resources and result in reduced access to support and role models.

7.3 The Expanded Family Lifecycle

A criticism of the lifespan development model is that it does not frame individual identity and development within the context of wider systems. The expanded family lifecycle model (Carter & McGoldrick, 2005) argues that the individual should be seen within the context of the family which itself has further systems acting upon it. The family is conceptualised as a system which is highly influential; it is the system into which we are born, live, and die, and is embedded within the larger social-political culture. They describe six stages or transitions of the family lifecycle, of which each involves certain emotional processes as well as associated 'second-order changes' which are akin to developmental tasks. These emotional processes and developmental tasks need to be achieved in order for the stage to be successfully navigated (see Table 1 below).

Table 1: The Expanded Family Lifecycle Model Adapted from Carter & McGoldrick (2005)

| Family Life Cycle Stage | Emotional Process of Transition | Second-Order Changes |
|---|---|--|
| Leaving home: single young adults | Accepting emotional and financial responsibility for the self | a. Differentiation of self from family of origin b. Development of intimate peer relationships c. Establishment of self in respect to work and financial independence |
| Joining of families through marriage: the new couple | Commitment to new system | a. Formation of marital system b. Realignment of relationships with extended families and friends to include spouse |
| Families with young children | Accepting new members into the system | a. Making space in marital system for children b. Child rearing, financial and household tasks c. Developing relationships with extended family to include parenting and grandparenting roles |
| Families with adolescents | Increasing flexibility of family boundaries to permit children's independence and grandparents' frailties | a. Shifting of parent/child relationships to permit adolescent to move into and out of system b. Refocus on midlife marital and career issues c. Caring for older generation |
| Launching children and moving on | Accepting exits from and entries into the family system | a. Renegotiation of marital system as a dyad b. Development of adult-to-adult relationships c. Relationships with in-laws and grandchildren d. Dealing with disabilities and death of parents (grandparents) |
| Families in later life | Accepting the shifting generational roles | a. Maintaining own and/or couple functioning and interests in face of physiological decline: exploration of new familial and social roles b. Support for more central role of middle generation c. Making room in the system for the wisdom and experience of the elderly, supporting the older generation without functioning for them d. Dealing with loss of spouse, siblings, and other peers and preparation for death |

As Table 1 shows, the family is seen as a highly complex system moving through time which incorporates new members only through birth, adoption, and marriage and from which members can only leave by death. At any point in time, different members of the family can be experiencing different stages of the lifecycle, and events on one level can impact greatly on

events elsewhere. Like Hendry & Kloep, Carter & McGoldrick (2005) acknowledge that cultural and historical factors play a huge role in how families define themselves and go through the lifecycle. For example, the concept of the family can vary according to culture; the typical White Western view is of a nuclear family but African Americans often view the family to consist of a wide network of people within the community which can go beyond blood ties and include close long-term friends. Cultural groups can also vary in their definition and timing of the stages and associated tasks, and can place greater importance and meaning on different events. For example, both Irish and Black cultures often place great emphasis (and expense) on funerals and will delay services until all family members can get there (McGoldrick, 2004). The motion of the family through the lifecycle is also seen to be influenced by the era in history in which the family is living and time in history in which each family member has grown up.

The model argues that individuals within the system operate at both an individual level according to their own genetic makeup, skills and abilities, but also within the wider contexts of immediate family, extended family, community and larger society. The relationship between the individual and the wider contexts is interactive in that an event at one level can impact upon the others. Stressors can occur at any point in time and can include developmental tasks (e.g. birth, migration), unpredictable events (e.g. untimely deaths, unemployment), and historical events (e.g. war, depression, natural disasters). Stress is often greatest at the transition points between one stage to another as families are forced to 'rebalance, redefine and realign their relationships' (Carter & McGoldrick, 2005, p.8). How well the individual and family overcome the stressor depends on a multitude of factors, both in terms of the amount of stress operating on the individual and family contexts, and in terms of the point in time in which the stressor occurs. Emotional tasks that cannot be resolved at appropriate stages are often carried forward and act as obstacles in future transitions and relationships. Given enough stress, any family can appear dysfunctional, and even a seemingly small stressor can cause great distress in a family in which there is a high level of stress acting on the individual and family contexts.

The strength of this model lies primarily in the flexibility of its structure which allows it to be applied to families of all kinds, irrespective of definition, culture, and time. However, it does contain some assumptions which may not be accurate within and between cultures, e.g. that all young people will leave home before getting married. Despite this, its systemic perspective is useful in that the wide variety of contexts that can impact upon the individual and family are described, acknowledging the complex interplay that can occur within and between systems.

7.4 Role of Clinical Psychologists in Supporting Transitions

The role of clinical psychology in the lives of people with learning disabilities often takes place within the context of the family or residential setting. Clinical Psychologists often find themselves working not only on a one-to-one basis with the service user, but also on a more systemic level to help facilitate problem solving and enhance family relationships. The stress and burden of care giving within the family home can have a huge impact on family members and can adversely affect psychological wellbeing. For example, Rodrigue, Morgan & Geffken (1990) found that mothers of autistic and Down syndrome children reported more disruptive planning, more caretaker and family burden, and more frequent use of self-blame as a coping strategy than mothers of developmentally normal children. Significant caregiver stress and burden can be felt even when the child is not cared for within the family home (McDermott, Valentine, Anderson, Gallup & Thompson, 1997). The 2001 Department of Health report entitled 'Family Matters', highlights how the emotional needs of carers are exacerbated by feelings of isolation and loneliness. It also reports that inaccurate stereotypical assumptions that carers from minority ethnic communities have extended family and support networks may make families from these communities feel even more isolated and lacking in support. This in turn can have a negative impact on the wellbeing of the disabled person (Mir & Tovey, 2003).

In the context of both the above models, it is often at the point of transition that individuals and families experience elevated levels of stress. When the levels of stress are perceived to exceed the amount of resources available, there can be a deterioration in psychological wellbeing. It is at this point that a Clinical Psychologist will try and intervene so that the stress does not become unmanageable and the transition and/or its impact can be negotiated successfully. Clinical Psychologists may work on a one-to-one level with individual service users or with the family system as a whole. Either way, the systems in which an individual or family are embedded need to be explored.

Clinical Psychologists, along with other professionals, can also become involved in transitions in terms of making decisions on behalf of service users if they are judged to lack the capacity to consent or make decisions for themselves. Professionals must attempt to make objective and informed judgements and act with the 'best interests' of the service user in mind (British Psychological Society, 2007). This inevitably places them in a powerful position whereby the decisions made have the potential to dramatically change the lives of service users and their families. Understanding more about the experiences of service users during and after times of transition would help to inform professionals about important issues for consideration.

8. Psychological Models of Stress and Coping

There is a great deal of variance in the way in which individuals and families experience stress during transitions. What may be experienced as a difficult transition for one family may not be for another, and what may be experienced by a family as a difficult transition at one time, may not be at another time. Stress and coping models have attempted to account for this variance.

Conway and Terry (1992) describe three dominant psychological models of stress and coping that have been proposed over the last few decades. The first drew upon psychodynamic principles and conceptualised coping as an ego process that was employed to reduce tension and distress (e.g. Haan, 1977). This approach has been criticised, however, by Lazarus & Folkman (1980) for its assumption that coping is always the most preferable response to stress, thus confounding it with outcome. Research also struggled to corroborate the proposed tenets of these models (e.g. Harder, 1992).

The second approach suggested that coping was a personality trait and postulated that an individual would respond similarly to all kinds of stressful events. However, research has shown that individuals do not tend to react consistently to different stressors and that timing of the stressor can influence the way in which the individual copes (e.g. Cohen & Lazarus, 1973).

The third model of stress and coping, and the most widely recognised, was proposed by Lazarus and Folkman in 1984. Their 'transactional model of stress and coping' conceived of stress and coping as a dynamic process. They proposed that no event or situation is inherently stressful; it is the individual's appraisal of the situation which determines whether or not it causes stress. If a situation *is* judged to be stressful, an individual needs to draw upon an appropriate means of coping with the stressor in order for the stressor to be managed successfully. They suggest that there are two methods of coping: emotion-focused coping which deals with the emotional aspects of a stressful situation, and problem-focused coping which deals with the practical management of a situation. Successful coping can be described as, 'constantly changing cognitive and behavioural efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus & Folkman, 1984, p.141).

Generally, problem-focused coping has been found to be more adaptive, and has been associated with higher levels of psychological wellbeing. However, Lazarus and Folkman propose that in some situations emotion-focused coping can be more adaptive. They suggest that the method of coping that should be used depends on the extent to which the stressful situation is perceived to be controllable. If the stressor is deemed controllable the individual

should draw on problem-focused coping to deal with the stressor; however if it is deemed uncontrollable, the individual should draw upon emotion-focused coping to deal with the stressor. This is because in situations perceived as controllable, it is possible to alleviate the stressor by employing direct practical problem-based solutions (such as learning new skills, developing new standards of behaviour, or finding alternative means of gratification). However, in situations perceived as uncontrollable, problem-based solutions will be ineffective and instead the individual would benefit from using emotion-focused strategies (such as wishful thinking, avoidance or minimising) to control their emotional reactions to the stressful event. This necessary match between perceived controllability and method of coping is referred to as the 'goodness-of-fit hypothesis'.

This theory underpins many of the ideas in Hendry & Kloep's lifespan model of developmental change. Transitions are experienced as difficult when the individual or family perceives the transition to be stressful, and then uses a mismatched coping style to deal with the situation. This in turn could lead to a deterioration in psychological wellbeing. In times of difficult transitions, it may be that Clinical Psychologists need to support individuals and families in developing action-focused strategies to cope with the more practical aspects of transitions, and emotion-focused strategies to deal with the difficult emotions that often occur throughout the course of a transition. Developing emotional strategies may be most important when transitions occur suddenly, and appear to be out of the control of those involved, such as in times of crisis when a main carer has become ill or has died. Finding out more about the way in which stress is experienced and managed by service users and families at times of transition could potentially lead to more effective support being offered by psychological services and other professionals during the transition period.

9. The Transition of Leaving Home for People with Learning Disabilities

One of the transitions faced by many traditional Western families is when adult children grow up and leave the family home (the first transition described by Carter & McGoldrick). However, for young people with learning disabilities this transition may be delayed considerably or may not happen at all. The majority of people with learning disabilities are cared for within the family home by relatives, but as people with learning disabilities are beginning to outlive their parents, placement outside the home into supported accommodation may become necessary. Emerson & Hatton (2008) predicted that by 2011 public agencies in England will need to provide residential services for an additional 12,000 older adults with learning disabilities and that this figure will increase to 20,000 by 2021.

As noted earlier, approximately 70% of people with learning disabilities are living with a family member or partner, 4% are living alone, with the remainder living in some kind of supported accommodation (CEDR, 2008). Often those in supported accommodation have little choice or control over their lives. However, when comparing such residential services to family settings, research has shown that although people with learning disabilities living at home receive considerable support from family members, they also tend to use fewer services, have fewer friendships with people their own age, and are more likely to be obese. They are also at risk of experiencing an emergency transition into residential services if advance planning for future care does not occur (Seltzer & Krauss, 2001). These findings suggest that people with learning disabilities living within the family home may be isolated from and take part in fewer activities than those living outside the home. This may reflect the lack of opportunities to become more independent and assertive as described by Shepperdson.

9.1 Reasons for Moving Out of Home

Essex, Seltzer & Krauss (1997) conducted research into factors that precipitated residential transitions and found three transition profiles which have their basis in lifecycle models (Carter & McGoldrick, 2005) and stress coping models (Lazarus & Folkman, 1984):

1. *Normative launching* whereby the person with a learning disability moved out of home at about the same time and for similar reasons to most non-learning disabled people
2. *A move as a coping mechanism in response to a 'stress process'* whereby the transition was precipitated by difficult events or situations
3. *Postponed launching* whereby a move occurred much later in life and occurred as a precautionary strategy in preparation for when the carer would no longer be able to cope

Alborz (2003) interviewed 18 carers of people with learning disabilities who had recently made the transition from the family home into residential services and found that transitions fitted into these three profiles. The majority of moves (78%) were due to a 'stress process' and Alborz suggested this profile should be extended to incorporate three types of stress process moves – forensic (involving actual or near intervention by the police), family (problems such as parental ill health or marital breakdown) and service (relating to a lack of service provision). As highlighted earlier, lack of access to services is of particular relevance to minority ethnic families.

9.2 Planning of Residential Transitions

The high proportion of moves in response to a stress process reported in the study by Alborz highlights the need to plan residential transitions in advance. Not only can such stress

moves be highly distressing for the service user and those around them, but they also inevitably lead to less choice and control over future accommodation as service users are limited to what is available at that moment in time. Forward planning can increase the amount of choice and control for service users and their families about how and where they live, an issue that has been highlighted in the Department of Health's (2005) consultation paper entitled *Independence, Wellbeing and Choice*.

However, research has shown that there tends to be a general avoidance of planning in most families. Several American studies conducted in the 1990s revealed that carers were reluctant to make concrete future plans; Kaufman, Adams & Campbell (1991) reported that of 57 older parent carers of adult children, 51% had no plans for the future, and similar results were reported by Freedman, Krauss & Seltzer (1997) with a larger sample of 340 mothers. British studies have reported similar figures; in reviewing the care plans of 18 relatives caring for people with learning disabilities Prosser (1997) found that only 28% had made any concrete plans suggesting that future moves in response to crisis such as ill health or death of the main carer were likely. McConkey, McConaghie, Barr & Roberts (2007) also reported similar findings in an Irish sample. They suggested that services need to support families in making future plans by improving person-centred planning and increasing information provided to carers about residential options and their relative costs and benefits. Similarly, in a study conducted by Gilbert, Lankshear & Peterson (2008) which asked older family carers in Plymouth about their views on the future, responses highlighted a lack of access to information about possible housing options, a lack of proactive support from social services, and tensions between family carers and professionals due to differing perceptions of need. These issues appeared to be compounded by poor communication between the housing and social work departments. These issues were also reported in a study by Bowey & McGlaughlin (2007) who again found that over half of their respondents were not ready or were unwilling to make future plans. Reasons given by carers for this reluctance included a perceived lack of need due to the presence of two carers, a lack of knowledge of the housing options available and the timescale required to secure housing, feelings of guilt and difficulties in letting go, and the presence of mutually supportive relationships.

The above studies also examined factors which appeared to increase the likelihood of making plans. These included greater contact with friends and family (Kaufman, Adams & Campbell, 1991), being a single carer, caring for someone with behavioural problems (often linked to higher caregiving burden), and having a child with mild or moderate as opposed to severe or profound learning disabilities (Freedman Krauss & Seltzer, 1997). The presence of a reciprocal caring relationship, as highlighted in the Bowey & McGlaughlin study, has been

reported by several researchers (e.g. Walker & Walker, 1998; Grant, 1986), and appears to result in a reduced probability of making future alternative housing plans. This mutually dependent relationship is likely to become more significant as the carer ages and comes to rely on the service user more for support. Bowey & McGlaughlin (2007) also found that families' experience of respite services also affected their willingness to plan for the future. Having short breaks acted as a 'preparation tool' for experiencing time away from family members and also gave families an insight into services.

9.3 Planning of Residential Transitions in Minority Ethnic Communities

The above studies provide important insights into the complex process of how and why families plan (or resist planning) for the future needs of people with learning disabilities. None of the studies however used non-White families, and none asked the service users themselves about the future. Little is known about how minority ethnic groups plan for the future, and whether or not they are similarly resistant to making such plans.

In a study specifically focusing on minority ethnic communities, Hubert (2006) interviewed 30 carers about their views of services. She found that many reported a system of mutual caring as described above, and that although this had benefits to the carer, it had also led to some families remaining independent of external services. Approximately half the main carers were in poor health but several were reluctant to inform service providers as they feared that they would be prevented from continuing to care for their adult child within the family home. Many carers also reported feeling socially isolated; while this is a common feature of being a carer Hubert reported that this appeared to have been compounded for many of the carers in her study due to cultural isolation and language problems. Hubert also found that although many carers had concerns about the future, 21 out of 30 had made no future plans. On the whole, carers were resistant to their child going into residential care, but were also opposed to the idea that another child should take on the caring role. Fears about the future were so strong that in some cases mothers expressed the desire that their child would die before they did. Hubert readily acknowledges that it is difficult to know to what extent the views of carers in this study were affected by their cultural identity. It seems that the carers had similar fears and concerns as those expressed by the White carers in the above studies; however Hubert argues it is possible that factors such as social isolation (and thus more mutually dependent relationships) and lack of information about services may mean that for carers from minority ethnic communities, thinking about the future is even more daunting and distressing.

9.4 Experience of Residential Transition

Although several studies have explored how families plan for residential transition from the family home, few studies have looked at the experience of the transition itself and its impact on the service user and family. As noted earlier, transitions can be difficult times, and can place people at increased risk of mental health. As a result, it is often at times of transition that Clinical Psychologists become involved with service users and families. The transition of moving away from home can be a difficult experience for anyone, but for people with learning disabilities it can be particularly challenging, particularly if precipitated by a stress process, as often appears to be the case for people with learning disabilities.

Alborz's (2003) study did examine the process of transition, but this research primarily focused on identifying the precipitating causes for the transition rather than the experience of the transition itself. It also only interviewed carers rather than service users themselves, and all but one of the families was White British so there was very limited exploration of the experiences of people from minority ethnic communities. Bigby (1996) explored people's experience of transition into residential services, but this Australian study focused primarily on the presence or absence of plans preceding the move. This is one of the few studies however which involved interviewing service users themselves as well as carers and service providers.

Other research has explored the extent of family involvement in the care of their child after a move to residential services has been made. Baker & Blacher (1993) found continued family involvement to be very high two years after a child with learning disabilities moved away from home, a finding that was replicated by Blacher & Baker (1994). In the latter study, families reported a mixture of feelings about placing their child in residential care, from feelings of guilt about having abandoned them, to feelings of happiness but also stress when the child made a visit home and relief when the child left again. Most families reported an improvement in their family life in terms of their recreation, social life and the adjustment of their other children. In a study exploring family involvement after transition of adult children to residential services, Seltzer, Krauss, Hong & Orsmond (2001) also found continued emotional involvement of mothers with their adult child, and improved sibling relationships. Most of these studies were carried out in America and so it is important to be cautious about generalisability. However, although the residential settings may not be fully comparable to those in the UK, it is likely that we can draw some parallels about the parent-child relationships.

Most of these pieces of research were quantitative in nature and did not explore the participants' experiences of transition in depth. The studies by Alborz and Bigby did use qualitative analysis to explore perceptions of transitions, but these studies focused on reasons

for transitions and plans rather than the experience of the transition itself. Few studies have been conducted from a psychological perspective, grounding the findings in psychological theory and understanding.

There is therefore a need for research which explores the experiences of people with learning disabilities who have made the transition from the family home into residential services. This research will address this need and some of the methodological limitations described above by interviewing service users from the African Caribbean community about their experience of transition into residential services. The findings will help Clinical Psychologists become more aware of the impact of residential transitions on mental health and psychological wellbeing for this particular ethnic group, and inform them of what can be done in practice to prevent or alleviate any distress experienced. On a wider scale, it is hoped that the findings will help to inform policy-makers and services about issues and provide examples of good practice.

The decision to focus specifically on the African Caribbean community is the result of several factors. As described above, despite the inferior access to and provision of services for people from ethnic minority communities, the needs of such communities have largely been overlooked in relation to learning disability research. The research that has been done has tended to focus on South Asian families (Mir et al, 2001). The African Caribbean population has been largely ignored, even though they are at a higher risk of being diagnosed with mental health problems than other ethnic groups (Fernando et al, 1998) and research clearly shows that transitions increase vulnerability to poor mental health (e.g. Schulenberg, Sameroff & Cicchetti, 2004). In addition to this, the African Caribbean community appears to be over-represented in residential services (Healthcare Commission, 2007). This research hopes to go some way in readdressing the balance in terms of the paucity of research exploring the difficulties faced by the African Caribbean community. Targeting the most marginalised group, may also lead to standards being raised for all groups.

The goal of this research is to explore the experiences of the African Caribbean community in their own right, not in comparison to other ethnic groups. It is anticipated that the findings will inform service providers and professionals about the specific issues faced by the African Caribbean community, highlight any cultural needs, and allow recommendations to be made which will address any issues that emerge.

10. Research Question

In light of the above, this research will provide an answer to the question:

How do African Caribbean people with learning disabilities experience the transition into residential care?

11. Chapter Summary

This chapter gave an overview of the relevant literature in the areas of learning disability, ethnicity and mental health with a particular focus on transition. It highlighted the gaps in the literature regarding the experience of transition for people with learning disabilities from minority ethnic communities and gave a justification for the research question under study. The following chapter gives a summary of the methodology used in the study and a description of the procedure that was followed.

CHAPTER TWO: METHOD

1. Chapter Overview

This chapter begins with an overview of my own position in relation to the research topic in order to give the reader an insight into my personal and professional background and how it may have impacted upon the research process. This is followed by a justification for choosing the qualitative methodology of Interpretative Phenomenological Analysis (IPA) along with a description of the ways in which quality was maintained. The sampling, measures and procedure used in the research study are then summarised. The chapter concludes with the consideration of ethical issues and dissemination of results.

2. Reflexive Statement

2.1 Interest in the Research Topic

My interest in carrying out this research stems from having worked within two separate learning disability NHS services and witnessing firsthand the many challenges both service users and their families face throughout their lives. In particular, I have worked with several service users who have been struggling with the transition of moving out of the family home and have also encountered families in which there has been a tension between the needs and desires of the service user and the family with whom they live. When working in these services, helping people to cope with the prospect or the consequences of moving out of the family home was often a large part of my role, yet I found little research available which provided an insight into the experiences of service users or their families, or which provided recommendations for clinical practice.

My interest in minority ethnic communities comes from both professional and personal experiences. In one of my posts working with people with learning disabilities, I worked predominantly with minority ethnic communities and gained some insight into the difficulties that can arise for such individuals in accessing services and getting needs met. In addition to this, I have experienced being part of an ethnic minority group myself whilst teaching English in Japan for eighteen months, during which time I encountered many difficulties in receiving appropriate health care in a culture and society that was vastly different to my own.

2.2 Personal Characteristics

As a White British person I currently belong to the majority ethnic group in the UK and come from a different ethnic background to that of my participants. I am also different in

terms of my gender and lack of direct experience of having a learning disability. I had concerns that the differences between myself and my participants would place me at a disadvantage as a researcher, that perhaps it would be too difficult to attempt to understand the perspective of a group of people with whom I share few characteristics. I was also concerned that the participants in this study could be wary or distrustful of talking to me. However, at the same time, I was aware that being different allowed me to take on the position of a curious outsider, someone who could ask questions without assuming that I already knew the answers.

2.3 Theoretical Background

As a clinician, I consider myself to be influenced by many psychological frameworks including systemic, cognitive behavioural, personal construct and psychodynamic models. However, I am particularly influenced by the theoretical constructs underlying Cognitive Analytic Therapy, and did at times find myself making sense of participants' experiences using ideas from this therapeutic framework (e.g. thinking about participants' family relationships in terms of reciprocal roles). My supervisors were aware of these influences and helped me to notice when I was unintentionally using this framework to shape my analysis so that I could pull back and view the data in a more mindful and critical way.

2.4 Research Experience

Before embarking on this research, I had had some limited experience of carrying out research, most of which was quantitative in nature. IPA, and to some extent qualitative analysis as a whole, is a relatively new challenge for me and although it has been demanding I have enjoyed having the opportunity to explore individual experiences in depth. However, being a novice researcher may have had some impact upon the quality of the analysis; I have tried to put in place as many safeguards as possible to ensure the quality of the research. These are outlined further on in the chapter and in more detail in Chapter Four.

3. Qualitative Research

The data in this study were collected and analysed using qualitative methodology. This type of research allows the researcher to address questions that do not lend themselves to quantification, such as the nature of people's experiences including their thoughts, feelings, and beliefs (Barker, Pistrang, & Elliott, 2002). It enables individuals to be studied in depth, resulting in the collection of a rich source of data. Qualitative methodology also lends itself to research which is exploratory in nature and which seeks to generate knowledge about an as

yet undiscovered area, rather than to test hypotheses that have already been formed. It was therefore a useful means of exploring the research question of this study.

3.1 Types of Qualitative Research

A variety of approaches can be used within qualitative methodology. Barker et al (2002) argue that these approaches can be conceptualised as belonging to either the phenomenological or the social constructionist tradition. Broadly speaking, phenomenologists come from a more realist position and attempt to understand the thoughts, feelings and perceptions of their participants through accessing experiences via language. Whilst they acknowledge that it may be impossible to gain direct access to participants' lives, they argue that it is still possible to gain some kind of understanding of people's experiences, ways of thinking and actions through language (Reicher, 2000). Social constructionists on the other hand, come from a more relativist position, in which it is thought that what we perceive and experience does not represent a direct reflection of reality, but must be understood only as a version of events (i.e 'there are knowledges rather than knowledge' Willig, 2008, p.7). Thus, language itself is thought of as a social invention that does not necessarily reflect the individual's thoughts and feelings but is used as a means of structuring reality.

For this piece of research, a phenomenological approach seemed most appropriate as such an approach is concerned with generating knowledge and information about experiences and also provides a systematic approach to collecting and analysing data. The two most prominent phenomenological approaches to qualitative research are Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA). GT is described as being suited to social psychology research where social processes and practices are examined (Willig, 2008) and it ultimately aims to develop an overarching theory of experience by sampling different groups with potentially conflicting ideas. Although this is an older, more established approach than IPA, due to its sampling strategy it was felt that GT could potentially lead to the views of service users becoming lost or overshadowed rather than being heard and valued. This is in contrast to IPA in which the focus is on understanding the unique experiences of a homogenous sample in order to give voice to a specific group of people.

IPA is 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' (Smith & Eatough, 2007, p.36). It places less emphasis on realist notions than GT and is described as being a more 'psychological' approach as it shares constructs and ideas with mainstream psychology (Smith, 2004). For these reasons, IPA was considered to be the most appropriate research method for this study.

4. Interpretative Phenomenological Analysis

In IPA, the researcher is interested in learning about the participant's psychological world and their experiences of particular phenomenon through open discussion (Smith, Jarman & Osborn, 1999). The phenomenological aspect of IPA refers to discovering how people experience things, i.e. what an experience is like. The researcher attempts to produce a 'coherent, third-person and psychologically informed description' of how the participant views their experience. The interpretative element of IPA aims to position the initial 'descriptive' analysis in relation to a 'wider social, cultural, and perhaps even theoretical context' (Larkin, Watts & Clifton, 2006, p.104). The researcher does this by reflecting on how people make sense of their experience and then interpreting this sense-making in order to further understand it. In this way, data analysis is dependent on the researcher making subjective interpretations of the participant's own interpretation, a process referred to as the 'double hermeneutic' (Smith, Flowers & Larkin, 2009, p.3).

Data are typically collected via the use of interviews from which transcripts are written and analysed. One of the strengths of IPA is that it provides researchers with a set of flexible guidelines on how to analyse data which the researcher is free to adapt according to their research aims. Analysis follows a systematic process incorporating several stages (see Table 2 on the following page). This process is cyclical in nature, and the original text should be frequently consulted in order to ensure emerging themes and cluster themes relate to the original data.

Table 2: Stages of Data Analysis in IPA

Adapted from Smith, Larkin & Flowers (2009)

| Stage of Analysis | Description of Stage |
|-------------------|--|
| 1 | <p>Initial readings of the transcript</p> <p>Individual transcript read and re-read several times, at times whilst listening to the interview recording. Researcher notes down their most powerful recollections of the interview in an attempt to bracket these thoughts off and look at the transcript with fresh eyes.</p> |
| 2 | <p>Initial noting</p> <p>Transcript read and exploratory notes and comments noted down in the right hand margin, focusing in particular on descriptive, linguistic and conceptual comments. Look for similarities, differences, echoes, amplifications and contradictions in text.</p> |
| 3 | <p>Developing emerging themes</p> <p>Emergent themes are identified and listed in the left hand margin, and incorporated with the researcher's interpretations.</p> |
| 4 | <p>Searching for connections across emergent themes</p> <p>Researcher begins to chart or map out how the emergent themes fit together, resulting in the emergence of superordinate and cluster themes.</p> |
| 5 | <p>Producing a summary table of themes with illustrative quotes</p> <p>Summary table produced listing cluster labels, subordinate themes, corresponding quotations, and references to where the relevant extracts can be found in the transcripts.</p> |
| 6 | <p>Moving to the next case</p> <p>The process is repeated with the next case.</p> |
| 7 | <p>Looking for patterns across cases</p> <p>Summary tables for each case are integrated and a final analysis is produced showing connections for the group as a whole.</p> |

Figure 2 below gives an example of the coding of transcripts during the analytic process.

Figure 2: Examples of Stages 1-3 of IPA Coding - Darren

| | | |
|---|--|--|
| <i>Unable to be independent, controlled</i> | <p>P: She used to be too bossy. She used to do everything for me. I didn't like it but I decided well I'll just let her carry on and do what she wants 'cause it's her house and you can't complain so...</p> | <p><i>Bossy/ controlling, did everything for me Disliked this 'decided' 'let her' 'her' house, did not feel at home..Unable to complain, cannot speak up</i></p> |
| <i>'Decides' to submit, trying to regain control?</i> | <p>I: Mmm... so how did you end up moving back home?</p> | |
| <i>Lack of power and control, unheard. No ownership over home</i> | <p>P: I don't know. My social worker pushed me into going back home. But I said to her I don't want to go back home. I knew that me and my Mum were going to argue, and I'd known then that I should never have moved back home. So I carried on where I was, then get my own house or flat or whatever... instead of moving into hostel to hostel.</p> | <p><i>Pushed into, done to, against will Said he did not want to go home He knew better family conflict carried on, endured get own house – solution is to move Hostel to hostel... many moves, unsettling</i></p> |
| <i>Lack of control or choice</i> | | |
| <i>Own opinion not listened to or heard, no voice</i> | | |
| <i>'Best interests'?</i> | | |
| <i>Move as a solution rather than solving difficulty</i> | | |

4.1 Ensuring Quality during the Research Process

IPA acknowledges that the process of data collection and analysis is a dynamic one, from which the researcher cannot be fully detached. Reflexivity is imperative throughout the research process, so that the researcher is open and honest about their own thoughts, beliefs, prejudices, assumptions and developing hypotheses (Starks & Brown Trinidad, 2007). Section 2.1 at the beginning of this chapter outlines my own personal stance in relation to the research topic, and describes my professional, cultural and theoretical background. This has been included in order to allow the reader to have some insight into my role in the research process (Mason, 1996).

Researcher bias was minimised through several forums. Prior to the interviews taking place, I noted down my preconceptions and ideas about the outcome of the research in order to be aware of my views from the outset. I also kept a reflexive journal throughout the research process in which I detailed my thoughts and ideas about the study as it progressed. In addition, credibility checking was carried out in order to increase the validity of the data analysis. This involved both the academic supervisors and a peer researcher analysing a sample of the transcripts to ensure that the emerging themes were consistent with those that I had identified. These quality checks are discussed further in Chapter Four.

5. Sampling

In IPA, participants are selected specifically because they have undergone the experience under investigation and can thus provide the researcher with insight into that experience. Therefore, sampling is carried out purposively rather than through randomised probability methods.

5.1 Inclusion Criteria

Smith, Flowers & Larkin (2009) argue that the aim of IPA is to explore a small homogenous group in detail. This is advocated not to privilege one group's experience over another, but in order to create some understanding of one group's experiences so that further research may be carried out with other groups and a broader picture can gradually be developed for larger populations. In this study, participants had to be over the age of 18, have a learning disability, and identify themselves as being African Caribbean. Participants also had to have moved out of the family home at least three months prior to their participation in the study so that their experiences post- as well as pre-transition could be explored. It was felt that these inclusion criteria made the sample sufficiently homogenous. In order to ensure that an adequate amount of data was collected, participants who did not have the required verbal

skills to take part in a semi-structured interview were excluded from the study. Participants who were not deemed to have capacity to consent were also excluded.

When the study was initially being designed, it was hoped that a family carer who had supported the service user when they were living in the family home would also be interviewed. As Clinical Psychologists often support the families of service users during times of transition in addition to service users themselves, it was felt that it would be useful to gain insight into how family carers make sense of the transition of their relative moving out of the family home. However, when investigating the possibility of recruiting family carers, it was found that the majority of carers were either reluctant or unable to participate. Recruiters reported that this appeared to be because most moves occurred in response to a crisis and thus family carers were too distressed to take part or were unable to participate due to illness or bereavement. As a result, it was decided that it would be too problematic to recruit family carers to the study, particularly as any that would be recruited were likely to be those that had not experienced a transition in response to a crisis, which would bias the sample and prevent crisis moves being represented. As the experiences of service users has not been explored in previous research, it was felt that aiming to explore their experiences constituted an important enough study in its own right.

5.2 Sample Size

Six participants took part in this study. As IPA is qualitative in nature and involves the detailed case-by-case analysis of transcripts, small sample sizes are recommended in order to allow the researcher to explore cases in as much depth as possible (Smith & Osborn, 2003). Analysis of larger data sets can result in the loss of 'potentially subtle inflections of meaning' (Collins & Nicolson, 2002, p.626). In their 2009 book, Smith, Flowers & Larkin advocated that doctorate students should aim for between four and ten interviews but that as IPA is concerned with the detailed accounts of individual experiences, smaller samples can often yield more thorough and complete analyses. Turpin et al (1997) report that in clinical and health psychology research there is some consensus that six to eight participants is appropriate for IPA research. This amount of data should produce enough information about similarities and differences between participants without it being overwhelming. In accordance with these recommendations six participants were interviewed in this study.

5.3 Recruitment

Participants were recruited from the following NHS and voluntary organisations:

1. The Psychology Department of the NHS Leeds Learning Disability Team
2. 'Roots', a group of people with learning disabilities from the African Caribbean community who deliver training and consultancy
3. Keyring, a supported living network for people with learning disabilities
4. St Anne's Community Services, an organisation which secures housing for disadvantaged people including people with learning disabilities

In order to recruit participants, the researcher met with the lead and/or the team of each of the organisations and gave them information about the study. Clinicians or keyworkers then identified any service users that they felt met the inclusion criteria. Potential participants were then approached by their relevant clinician or keyworker and given a brief letter (see Appendix 1) explaining the study and asking them if they would be interested in meeting with the researcher to discuss the research further. If potential participants agreed to this initial meeting they were asked to provide the researcher with their contact details so that a meeting could be arranged.

An initial meeting was then set up between the researcher and the potential participant at a location preferable to the participant. The participant was informed that they could have other people present at this meeting if it would make them feel more comfortable. At this meeting, participants were given an information sheet (see Appendix 2) about the study and were able to ask any questions. They were then given a week to think about their decision before they were contacted again by the researcher to find out whether they wished to take part in the research.

If they did wish to participate, a time and location preferable to the participant was arranged for the interview to take place. Capacity to consent was assessed in advance by the clinician or keyworker, and at both the initial meeting and the interview by the researcher.

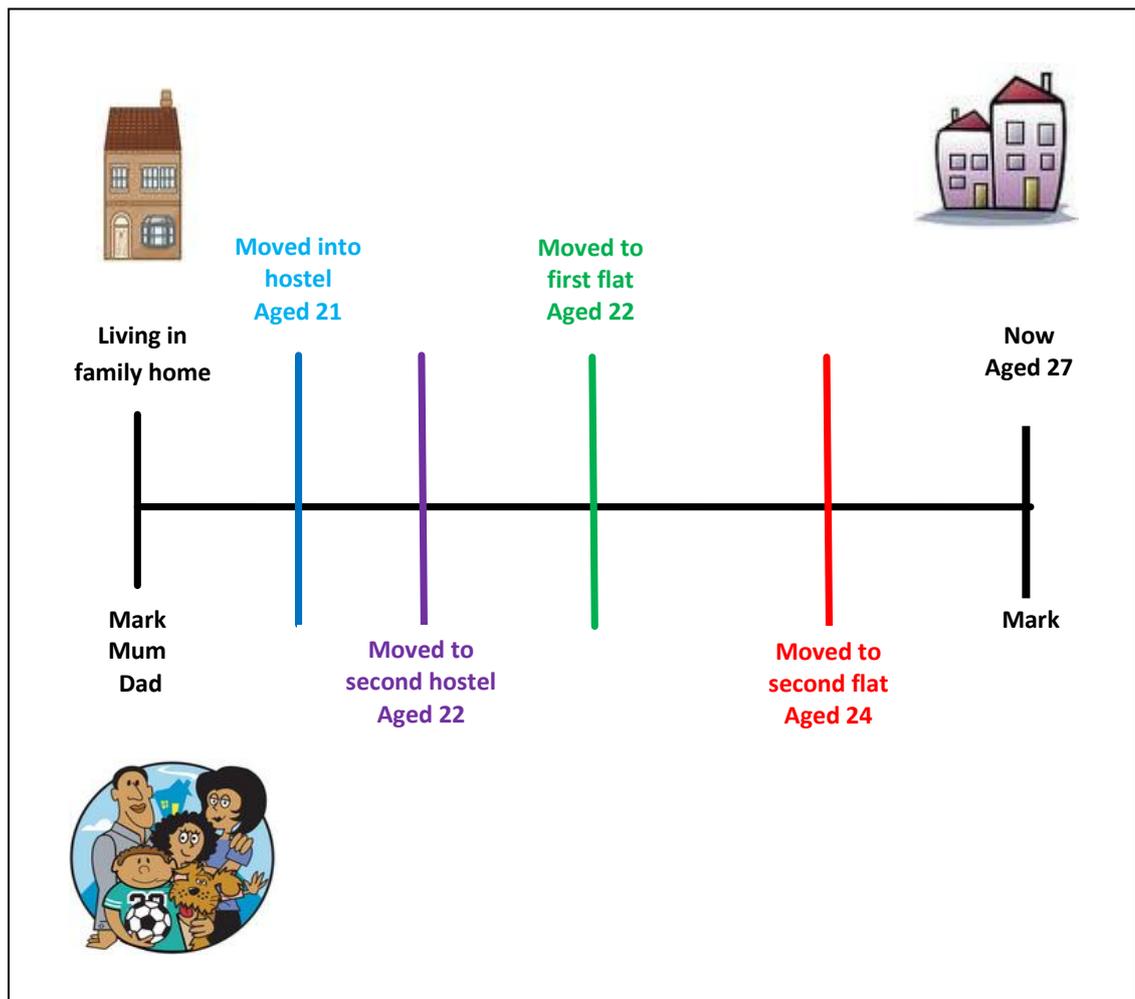
6. Measures/ Data Collection

Although data collection methods such as focus groups or written accounts have been used with IPA, the most common and recommended method is semi-structured interviews (Brocki & Wearden, 2006). Semi-structured interviews, 'allow the researcher and the participant to engage in a dialogue whereby initial questions are modified in the light of the participants' responses and the investigator is able to probe interesting and important areas which arise' (Smith & Osborn, 2003, p56.). The researcher aims to enter the social and

personal world of the participant, who is free to talk about their experiences at their own pace. This method of data collection facilitates a rapport between the researcher and the participant, gives the participant greater flexibility and control over what they wish to discuss, allows the interview to stray into novel areas the researcher had not considered, and tends to produce very rich data.

An interview schedule consisting of a set of open-ended non-directive questions was developed to guide the interview (see Appendix 4). The interview schedule asked the participant to complete a timeline and then talk through the experience of their residential transition(s) chronologically with a particular focus on the move out of the family home. Figure 3 is an example of what one of the timelines looked like; an actual example is not provided as this would jeopardise confidentiality.

Figure 3: Example of a Timeline Constructed during the Interview



Prompts asking about feelings, friends, family relationships, daily activities, level of support and overall quality of life throughout the transition were included in the interview schedule as these reflected themes in the literature to date as discussed in Chapter One. Prompts about transition planning were also included in order to determine whether the transition was in response to a crisis and to explore how this affected the transition process. Questions about the perceived influence ethnicity had on the participant's experience of transition were also asked in order to elicit any issues that may be important to this particular ethnic group. In order to encourage participants to talk about their experiences in relation to their feelings, a set of African Caribbean emotion cards (obtained from www.dunedinmultimedia.com) were used when necessary to prompt discussion of feelings at certain times of the transition.

7. Procedure

The interview procedure was informed by a consultation that took place with several service users. Ideas from this consultation process were incorporated into the interview protocol.

7.1 Service User Consultation

Prior to the commencement of data collection, drafts of the initial letter, information sheet and consent form (see Appendix 1-3) were discussed with a panel of African Caribbean service users, all of whom had a learning disability. This development work was carried out in order to ensure that the information provided to participants was as relevant and meaningful as possible and that the language and diagrams used were appropriate and clear. Feedback from the panel was largely positive; suggestions mainly focused on the use of alternative images. The panel also suggested that both the researcher and participant should be given three coloured cards during the interview which could be held up or pointed to by either party at any time. This is a system which is commonly used in learning disability meetings and is one with which many service users are familiar. A red card indicated that the interview should be stopped or paused, an orange card meant that the person did not understand or needed something repeated, and a green card indicated that they were happy to continue. This card system was incorporated into the interview as a means of enhancing the communication between participant and researcher.

7.2 Interview Protocol

Participants were given a choice as to the location of the interview. Three chose to be interviewed in the home of their keyworker, two in the offices of their supported living service,

and one in an interview room at the University of Leeds. Participants were asked to describe what they could recall about the study and were given time to ask any questions about the research. Capacity to consent was then assessed before they were asked to sign a consent form (see Appendix 3).

Interviews lasted between 60 and 90 minutes and were recorded with a digital voice recorder. Consent was checked again at the end of the interview and participants were asked if there was anything they had said that they did not want to be included in the final transcript. Participants were then paid £15 for their time.

Immediately after the interview I noted down any reflections that I had about the interview process and how it had unfolded. These reflections included the impressions of the participant, any points at which the participant had seemed uncomfortable, any emotions felt in response to the participant, and any apparent themes. These notes served several purposes. My initial impressions and emotions were noted in order to become aware of my assumptions about participants and bracket them off in advance of the analysis in order to be more objective. Notes about awkward moments served as reminders and prompts for the analysis, and particularly helped when it came to reading transcripts through and reflecting on pauses and the presence or absence of elaboration.

8. Ethical Considerations

Ethical approval was granted by Leeds (East) Ethics Committee on the 14th October 2009, and by the Research and Development Committee on 30th October 2009 (see Appendix 5 & 6).

8.1 Potential for Harm

All participants elected to have their keyworker or clinician present at the initial meeting and reported that this made them feel more at ease. All meetings and interviews were conducted at a location requested by the participants.

As semi-structured interviews can often last for an hour or more and can be quite intense, participants were given the option of having one long interview or two short consecutive interviews. Four of the six participants opted to have one long interview, one opted to have one interview with a short break, and one opted to have two consecutive interviews.

The semi-structured interview asked participants to recall their experience of moving out of the family home. Research shows (e.g. Alborz, 2003) that such transitions often occur as a response to a crisis, and therefore it was possible that asking participants to describe this

transition could bring up memories of distressing events such as family illness, bereavement or breakdown. One of the strengths of the semi-structured interview is that it gives the participant a high level of control over what topics the participants want to cover and their level of self-disclosure. However to further prevent distress, all participants were fully informed about the nature of the research and the subject area in advance. They were also reminded of their right to withdraw from the study at any time, and their right to choose not to answer questions. No participants became distressed during the study, although two did elect not to answer a question and one did use the coloured card system to request a break. If a participant had become distressed, the interview would have been stopped and immediate support would have been provided.

8.2 Capacity to Consent

All participants had to be able to give informed consent to take part in this research. Capacity assessments were conducted by the participant's keyworker or clinician before they were approached to take part in the study, and again by the researcher both at the initial meeting and at the start of the interview. Any indication that the participant may have lost capacity to consent during the interview would have resulted in the interview being discontinued and the participant being withdrawn from the study.

Capacity to consent was assessed by the researcher in accordance with guidance from the Mental Capacity Act Code of Practice (2005), the Department of Health document entitled, 'Seeking consent: Working with people with learning disabilities' (2001) and the British Psychological Society's document entitled, 'Conducting research with people not having the capacity to consent to their participation: A practical guide for researchers' (2008). According to these documents, for a person to demonstrate capacity to consent they must be able to:

- Understand the information relevant to the decision
- Retain that information
- Use or weigh up that information in the process of making the decision
- Communicate the decision

Thus participants were given time to read through the information sheet and ask questions, and were then asked to describe the information in their own words, compare alternatives (e.g. 'What do you think will happen if you decide not to take part?') and finally indicate whether or not they wished to take part. This process was carried out at the initial meeting and was repeated at the start of the interview. No participants lacked capacity to consent and all agreed to take part in the interviews. One participant however did appear quite anxious and tired in his interview and so it was agreed that the interview would be

completed in two parts to minimise the intensity of the procedure and enable him to feel more relaxed and alert.

8.3 Confidentiality

All data collected in this study were confidential and were not made available to anyone other than myself my supervisors, and a peer researcher. All of the six interviews were recorded and transcribed with consent. Three of the six interviews were transcribed by the researcher and three by a professional transcriber who was asked to sign a confidentiality agreement (see Appendix 7). All data, including transcripts and audiotapes, were anonymised and given a number. Contact details and descriptive information, such as age and gender, were stored with only the number as an identifier as a document on the researcher's university network drive. During the process of transcription, personal identifying details such as names of persons, places, known landmarks etc were transformed so that personal details were not present in the transcript in order to safeguard against identification.

When writing up this report, care was taken to ensure the anonymity of participants and permission to use quotations was gained in advance. However due to the small sample size and the close knit community in which most of the participants are members, it is possible that people known to the participants may be able to identify them from their quotations. I have tried to guard against this as much as possible.

9. Dissemination of Results

Following the completion of the research, it is anticipated that the participants will be given a short summary of the results of the research, and will be informed about any publication details. The summary will be developed with a service user consultation panel in order to ensure it is as accessible as possible.

In addition to feeding back the results to participants, the findings will also be presented to relevant NHS trusts, teams and organisations. A copy of the abstract will go to the British Library and a complete copy of the thesis will be held by the University of Leeds library. It is also anticipated that the study will be written up for publication.

10. Chapter Summary

This chapter described the methodology and protocol that was followed throughout this study. The next chapter presents a summary of the analysis for both individual participants and the group as a whole.

CHAPTER THREE: ANALYSIS

1. Chapter Overview

This chapter begins with a brief description of the six participants. The individual analysis of each participant is then presented, followed by the analysis of the group. The decision to devote time to each individual's account in detail was made because it was felt that there were some strong and important themes that emerged from the individual analysis that may have been neglected if only a group analysis was presented. It was also felt that presenting individual accounts met one of the central aims of the research which was to give voice to a marginalised group of people. The group analysis draws together themes that were discussed by several of the participants in order to describe and interpret experiences common to the group as a whole.

2. Description of the Sample

Six participants were recruited, all of whom were male African Caribbean people with learning disabilities who had moved out of the family home. As the selection criteria for this study were quite stringent in order to ensure sufficient homogeneity of the sample, participants came from a relatively small pool of people living in the area. As a result, to protect the identity of the participants, the detailed description of each participant in the form of pen portraits has not been provided. Table 3 gives an overview of the samples' salient characteristics.

Table 3: Participant Characteristics

| Participant | Ethnicity | Move planned by participant? | Number of moves | Current living circumstances |
|--------------------|-------------------|-------------------------------------|------------------------|-------------------------------------|
| Greg | Mixed race | Unplanned | 4 | Supported living network |
| Darren | African Caribbean | Unplanned | 5 | Supported living network |
| Liam | Black British | Unplanned | 4 | Supported living network |
| Jack | Black African | Planned | 1 | Supported living network |
| Michael | Caribbean | Unplanned | 5 | Supported living network |
| Daniel | Black British | Unplanned | 2 | Group residential home |

As the table shows, although all participants identified themselves as being African Caribbean, each had their own preference as to the way in which their ethnicity was described (e.g. Black British, Black African). The possible implications of this are described to some extent in this chapter and in more detail in the discussion in Chapter Four.

Although participants were able to recount the nature and number of their moves in some detail and in a temporal sequence, many had difficulties recalling the exact dates and ages of their moves. However, information provided by the participants' keyworkers allowed such figures to be calculated. Participants were all aged in their twenties or thirties, and had moved out of the family home between four and twelve years previously.

Five of the participants' moves out of the family homes had not been planned by them, and occurred due to family conflict, stress or bereavement. Four of these five participants had at some stage been placed in a hostel prior to living independently; the fifth had been placed straight into a residential group home. One participant had planned his own move and had been able to move straight into a flat of his own.

3. Individual Analysis

Although the focus of the interview schedule was the experience of moving out of the family home, the majority of participants had actually experienced multiple residential transitions and wished to speak about them all. They also spoke more generally about the context of their everyday lives and the issues they had faced.

The themes that emerged from the interview data are applicable to and are drawn from participants' experience of residential transition. However, some themes also appeared to resonate with the more general context of participants' lives as an African Caribbean person with learning disabilities. In the individual analysis that follows, the themes for each participant are presented visually in a table, and are then described in turn.

Table 4: Participant One - Greg

| 1. Struggling with powerlessness | 2. Pride and status | 3. Limited resources | 4. Hoping for change |
|---|---|--|---|
| <p>Lack of control</p> <ul style="list-style-type: none"> • No say • Taken advantage of <p>Perseverance</p> | <p>Attempts to take on roles</p> <ul style="list-style-type: none"> • Parental role • Role of advisor • Homeowner | <p>Interpersonal conflict</p> <ul style="list-style-type: none"> • Difficulty getting along with others • Victim of racism • Jealousy of others <p>Poor conflict resolution</p> <ul style="list-style-type: none"> • Living on his own to avoid conflict • Moves as a response to stress • Aggression <p>Difficulties reinforced by others</p> <ul style="list-style-type: none"> • Feeling misjudged • Feeling unsupported | <p>Motivation for change</p> <p>Changes in relationships</p> <ul style="list-style-type: none"> • Differentiation of self from friends • Seeking more equal relationships <p>Desiring autonomy</p> <ul style="list-style-type: none"> • Being in control and having his own space |

3.1 Participant One: Greg

Greg was a man of mixed race who had moved several times since leaving home, often in response to stress. He currently lived on his own in a flat as part of a supported living network. He answered all my questions and did not appear anxious or distressed. At times Greg needed to be encouraged to elaborate on his responses; he did not have any difficulty understanding or responding but he did seem invested in a 'cool' self-image. He reported enjoying the interview and thanked me at the end for taking the time to listen to his story.

Theme One: Struggling with Powerlessness

Struggling to gain some sense of power and control over the events in his life seemed to be a common theme throughout Greg's experiences of residential transition. He repeatedly spoke of a lack of control, of being taken advantage of, and of having to struggle through life. All these experiences had left him feeling frustrated and vulnerable.

Lack of control

- *No say*

Greg often described having little say in decisions that affected him. He had experienced a series of residential transitions and often spoke about them as though other people had forced him to move from place to place, *'He got me kicked out', 'I was quite happy with my own place before she [partner] kicked me out'*.

This lack of control was an issue in other areas of his life too. For example, his previous partner with whom he had a child, rarely allowed him to see his son. This was something which he found difficult to cope with, *'I've got a little son but I can't see him so... I don't really go down and see him. I miss him. But she says she's busy'*. He also spoke of finding it difficult to get and keep a job, *'they fired me one day in recruitment'*.

These repeated experiences in which he had no say had left him feeling frustrated at not being able to achieve what he wanted.

- *Taken advantage of*

Greg also described situations in which he had been taken advantage of indicating that he could be quite vulnerable at times, *'cause people used to take money off me'*. It seemed that he used to have a group of friends who would lead him astray, *'I used to get in trouble myself but I changed. I'm not hanging out with my mates at the wrong place at the wrong time'*. This decision to change and the reasons behind it are explored in the third theme.

Perseverance

At times Greg seemed resigned to the idea of life being a series of challenges with which he had to battle, *'Struggle really. You just have to do what you have to do'*. However, despite his sense of powerlessness and his expectation of difficulty from life, he had not given up and continued to persevere, *'I just have to keep on... you just have to deal with the pressure'*, demonstrating a strong sense of determination.

Theme Two: Pride and Status

Greg had taken on several roles which he talked about throughout the interview. Many of these roles had arisen since his move out of the family home, perhaps in an attempt to carve out a new identity for himself away from his family. Such roles all appeared to be associated with a sense of pride and status and seemed to represent ways for him to gain acceptance from those around him.

Attempts to take on roles

- *Parental role*

There was a real sense of Greg trying to act in quite a parental way throughout the interview. He talked like this in relation to his neighbours but in particular he did this in relation to his father, often talking about him like a parent would a child. He did this both when describing when he lived at home, *'I was just looking after my Dad... I was mainly the only one there looking after my Dad really'*, and after he moved out, *'I let him chill with his friends... I call him sometimes to see how he is, to see how my Mum is'*.

Greg was of course unable to act this way with his own son, as he was not able to see him. Although the decision not to see his son seemed to rest with his ex-partner, Greg tried to turn this into a decision he himself had made, *'I decided if she's not letting me see him a lot then I'm not seeing him at all'*. He had also tried to engineer a role for himself as his child's disciplinarian, *'I just gave them my number. If he's been bad just phone me at my flat and I'll come down to tell you off. If he's not been bad you don't have to phone'*. Such statements perhaps represented an attempt to regain some level of control in relation to his son, as well as an attempt to regain his pride after being excluded from his son's life.

- *Role of advisor*

One role Greg had tried unsuccessfully to take on since moving out of home was that of an advisor to his friends. He saw himself as acting, *'more wiser than them'*, and said, *'I tried*

to give them advices but they don't listen. So I really don't chill with them'. As his attempts at this role had failed he had distanced himself from his friends, perhaps to protect his pride.

- *Homeowner*

Another more recent role was that of having his own home, *'I just look after my house... look after my home'*. Having a place of his own, or a *'crib'*, seemed to give him status.

Theme Three: Limited Resources

Greg spoke repeatedly of his difficulty coping with challenges. Often the challenges Greg faced were related to interacting with other people, something which he did not appear to have the skills and resources to do well. He also seemed to have unhelpful and limited ways of coping with such challenges, which were often reinforced by those around him.

Interpersonal conflict

At times Greg talked of finding relationships with others difficult. Sometimes this was because others did not respond to his attempts for friendship or tried to provoke him. At other times, Greg distanced himself from others because of racism. Greg often attributed such interpersonal difficulties to others being jealous of him. Such interpersonal conflict had caused not only his move out of the family home but also his subsequent moves from place to place.

- *Difficulty getting along with others*

Greg gave many examples of finding it difficult to interact with other people. He tended to describe himself as trying hard to get along with others but experiencing others as unable to get along with him, *'I just had to get on well with the neighbours but they weren't getting along well with me. I was getting along with them, they wasn't'*. He also described feeling like other people tried to provoke him, *'They tried to wind me up so I ignored them'*, *'Someone tried to wind me up and have a fight with me so I had a fight'*.

- *Victim of racism*

Since moving out of home, Greg had experienced racism in some of the places he had lived, *'Those people used to be racist down there'*. This racism occurred between all ethnic groups, *'No there was sometimes White people, Black people, some mixed. But they were all being racist so I moved out... They were just calling each other niggers and all that. People calling each other White people all the time'*. Greg understandably found this difficult to tolerate and ultimately moved house in order to avoid it, *'I just wanted to move out. I was going to move and leave all you lot to call each other names'*.

- *Jealousy of others*

Greg often attributed his interpersonal difficulties to other people's jealousy of him, *'People getting jealous of me, thinking how are you making so much money and we don't... Jealous of my money, my crib, even sometimes meeting my other mates'*. Jealousy was his predominant explanation for any kind of interpersonal conflict and perhaps was a way for Greg to protect his self-image and self-worth.

Poor conflict resolution

Greg appeared to have a very limited repertoire for dealing with difficulties. It seemed that for Greg, moving out had been a difficult experience as he had been placed in a flat on his own without having the resources he needed to cope by himself. He tended to deal with problems by avoidance, moving house or aggression. More recently as part of his attempts to change he had started to ignore other people or walk away to avoid getting into trouble.

- *Living on his own to avoid conflict*

To Greg, living on his own was a way in which he could stay out of the way of conflict with others. His initial reason for moving out of the family home was to avoid the arguments that had started between him and his father, *'So I could have my own space and so my Dad could have his own space. That's why I moved. I were gonna... we tried to...share. We tried to argue but it didn't work so...'*. When asked why he wanted to live on his own and not share with others, Greg replied, *'Cause it... you don't have to argue with them, me and the guy that came to fight or something... and then I'd be getting the blame'*.

- *Moves as a response to stress*

When Greg had difficulties with others, he often did not seem to know how to resolve them. When living with his father, with whom he did not always get on, he talked about how, *'We tried to argue but it didn't work'*. He also spoke of trying to complain to neighbours but of not being able to get himself heard, *'And the guy next door were playing loud music on the night time. So I complained and he didn't listen so that's why I moved to that one down there'*. For Greg, often the best way to resolve stress and conflict was to move house and try to start afresh, something which he had done several times.

Sometimes Greg moved as a result of practical problems, *'They could have sorted out the leaks in my houses what the neighbours done so... That's why I moved to that one'*, suggesting that he was unsure of how to solve problems and get the help he needed.

- *Aggression*

At times, Greg spoke of becoming aggressive as a way of protecting himself and responding to others, *'They tried to jump on me but I would jump on them instead'*. However, more recently he told of how he had begun to try and ignore or walk away from people who provoked him, *'They tried to wind me up but...ignored them', 'I'd just be out the way, so I'd just leave them to it and just get along on my own'*. He had adopted this strategy in an attempt to try and stay out of trouble and try and change people's perceptions of him as a troublemaker.

Difficulties reinforced by others

Greg spoke of his frustration that others perceived him as someone who caused or got into trouble. Since moving out of home he had been influenced by friends and had at times ended up with a bad reputation. This meant that he was often misjudged and not supported when he needed help.

- *Feeling misjudged*

At times Greg described feeling misjudged by those around him, and being held responsible for things he had not done, *'They were thinking that I was up to mischief but I wasn't', 'Coz the neighbours were thinking I was doing something but I wasn't'*. He felt like people tended to blame him for things and this led him to try and stay away from certain situations, *'I liked that one there [flat] 'cause it's out of the way from the crime that they're doing there down there so they don't blame me. And over there it's quiet and chilling'*.

- *Feeling unsupported*

It seemed that because people expected Greg to get into trouble, he was often given advice to keep quiet, *'just keep out of trouble and stay out of the way', 'just lock your door, just stay in, calm down and don't judge nobody'*. This may at times have been beneficial but it also meant that when he did need to be more assertive to get his needs met, he was not encouraged or taught how to do so. This sometimes left him feeling unsupported in solving problems, *'They could have helped me to stop the person playing music, playing loud TV. They could have helped me coz I complained, tried to get to sleep for college but they didn't listen... so I could have got that'*.

Theme Four: Hoping for change

Greg talked frequently of wanting to make changes to his life. Moving itself had always been an opportunity for Greg to make a fresh start and get away from his difficulties, *'It gives me the energy to start afresh'*. However, his desire for change seemed to be more than a desire for a new home. He also wanted to make changes to his relationships and his level of autonomy.

Motivation for change

Greg's desire for change was a recent one and when asked what had been the motivation behind it he said, *'I thought... I looked in my head, I'm going to start back where I used to come from'*, indicating a desire to stay out of the trouble he used to get into. He also spoke of wanting a more peaceful life. His new flat was a place that offered him a quiet, stress-free space, *'It's nice and quiet. I can chill 'cause I can sleep and that instead of hearing cars up and down, and there's no loud music... Mmm, that's how I like it. Peace and quiet, no stress'*.

Changes in relationships

- *Differentiation of self from friends*

As part of his desire to change, Greg had begun to spend less time with his old friends as he associated them with getting into trouble, *'They're still the same really. But I've changed. They're still doing crime... So I really don't chill with them'*.

- *Seeking more equal relationships*

Spending less time with his old friends had allowed Greg to spend more time with people who treated him like an equal, *'I chill with my cousins... 'cause they feed me, they get paid and I get paid so I'll go and feed them sometimes. Just won't chill with my mates sometimes 'cause they do my head in'*. He had also begun to make friends with his neighbour, which seemed like quite a new kind of relationship for Greg, *'I love to chill with my neighbour at my new flat... I was just going out when he said, "Do you want a bacon sarnie?" I'm about to go but I thought ok then. I wouldn't before though'*. It seemed that Greg had started to feel more trusting of others and had begun to feel worthy of being cared for.

Desiring autonomy

- *Being in control and having his own space*

Greg talked of valuing having his own home in which he could do whatever he liked, *'I'm glad I've got my own space, my own gear, my own friends, and I can do what I want'*. He felt he was more in control of his life, *'cause I can do what I want in my own house now. I can bring who I want'*. This was in contrast to when he lived with his father, *'I was just allowed to bring my lady friend, and that was it. But my mates, they weren't allowed in... 'cause he didn't trust my mates'*. This last statement reflects how when living in the family home Greg's father would act as his protector, not allowing him to mix with people he thought were a bad influence. Moving out of home allowed Greg the freedom and autonomy to make his own decisions about the people he mixed with. Whilst Greg valued this freedom and saw it as a

good thing, it may well have also left him more vulnerable to being taken advantage of by such friends.

Summary

For Greg, moving out of home seemed to represent a means of achieving autonomy and a sense of pride. However, living independently brought with it many difficulties and challenges for which he was often ill equipped and prepared to cope with.

Table 5: Participant Two - Darren

| 1. Striving for autonomy | 2. Held back by dependency | 3. Loss and rejection | 4. Not getting the right kind of care |
|---|---|--|---|
| <p><i>Desiring independence</i></p> <ul style="list-style-type: none"> • <i>Goal of participant vs. goal of others</i> • <i>The meaning of independence</i> • <i>Re-evaluation of independence</i> | <p><i>Feeling powerless</i></p> <ul style="list-style-type: none"> • <i>Done to</i> • <i>Unheard</i> <p><i>Difficulty trusting others</i></p> <ul style="list-style-type: none"> • <i>Broken promises</i> • <i>Feeling taken advantage of</i> • <i>Not feeling cared for</i> | <p><i>Loss of family</i></p> <p><i>Loss of friends and girlfriends</i></p> <p><i>Loss of professional relationships</i></p> | <p><i>Providing balanced support</i></p> <ul style="list-style-type: none"> • <i>Laidback versus bossy</i> • <i>Teaching</i> • <i>Need for boundaries</i> • <i>Timing</i> <p><i>Not feeling good enough</i></p> <ul style="list-style-type: none"> • <i>Feeling criticised</i> • <i>Being expected to fail</i> <p><i>Needing to feel respected and equal</i></p> |

3.2 Participant Two: Darren

Darren was an African Caribbean man who had not wanted to move out of the family home. He had experienced many moves, most of which had occurred against his will. He currently lived on his own in a flat as part of a supported living network. Darren was very passionate throughout the interview, and needed very little prompting. He spoke about his desire to be heard and listened to and was keen to share recommendations for professionals and services.

Theme One: Striving for Autonomy

Throughout the interview Darren often spoke of his desire to be able to cope on his own and be independent. This, together with wanting to have paid employment and a flat of his own, seemed to represent a wider goal of being autonomous.

Desiring independence

- *Goal of participant vs. goal of others*

Darren spoke of his desire to be independent and do his own thing. He saw moving out of the family home and living independently as a way of gaining this independence. It was unclear however whether this was something that Darren had always wanted for himself or whether it had been imposed upon him more recently by others. For example when asked what he did during his time at college (before he left the family home) he responded that college involved, *'being independent, standing up on my own two feet'*. He also reported that, *'My social worker told me to go into the hostel and be more independent'* and that when in the hostel he had to, *'do your own cooking as well, your own independence'*. Being independent was also something encouraged by his mother who instigated his move out of home.

- *The meaning of independence*

There seemed to be some disparity in the meaning different people gave to the term 'independence'. Darren used it to describe living independently and making his own decisions, *'I always wanted to live on my own. My own independence, nobody's telling you what to do and what time to come back'*. Other people such as the staff in the hostel appeared to see independence as doing things without support, *'you had to be independent for yourself more than sitting back and letting them do everything for you'*. This raises the issue of whether or not service users, families and staff have different goals in mind when talking about 'independence'.

- *Re-evaluation of independence*

Darren ultimately described feeling happy with his current level of independence despite the difficult journey he had gone through to achieve it. For example, when reflecting on being pushed out of home by his mother he started off saying *'Well she wanted me to go, but I didn't really want to go... I was feeling upset about it'*, but then a few moments later said, *'but then again I am more independent now'*. He also talked about how living independently made him feel more in control of his own decisions, *'You're doing things what you feel happy with. You're going home whenever you want, you're going to bed whenever you want, nobody telling you when to go to bed'*. Not only did Darren describe feeling proud of his achievements, but he also reported that others did too, *'She's [my mother's] proud of me, having my own place, being independent'*. His independence also appeared to have improved their relationship, *'We usually get on more now. 'Cause now I'm not going up there all the time and asking her for money she's more laidback... I don't need to depend on her'*.

Having paid employment

Darren also valued the times when he had had paid employment, *'When I was working... It was good pay as well, I miss the money'*. He talked about hoping to regain paid employment at the place where he currently volunteered, *'if they like me they have been saying that they'll get me a job at the end of it. So it's good'*. Having a paid job represented another source of the independence and autonomy that he was striving to achieve.

Successfully living on his own

After many moves, Darren desired to feel settled in one place, *'I've decided I'm fed up of moving around the place.... Yeah, it's about time that I just settled in one place and that's it'*. There appeared to be a sense of weariness around moving repeatedly and struggling with frequent changes, *'I love having flats but this is my last one. My last one, if this fails then that's it. I'm not getting no more after this one'*. It seemed that being able to successfully live on his own in one place would give Darren a sense of achievement about his abilities and make him feel even more independent and autonomous.

Theme Two: Held Back by Dependency

Darren's strong desire for autonomy was often compromised by his need to depend on others for support, making him feel powerless and lacking in control. His dependency on others was further complicated by his difficulty in trusting people due to his previous

experiences of being let down and taken advantage of. Being held back by his dependency often left him feeling frustrated, angry and disappointed.

Feeling powerless

- *Done to*

There was a strong sense of powerlessness throughout Darren's interview. Darren described many of his moves as occurring against his will, and as events that he felt forced to submit to against his will, *'I got pushed into moving in there. I wasn't happy but you have to do what they want you to do really'*. He also talked about how decisions were often made for him by his social workers and his family, *'They decided everything for me really. Well my Mum decided to get the social worker involved and move me out that way'*. He did not always get the opportunity to visit places in advance and at times he spoke about 'deciding' to go along with things, almost as if to convince himself that he did have some say in the matter, *'I was disappointed with it but I decided to do what they wanted me to do'*.

- *Unheard*

Throughout his residential transition Darren had often felt like his voice had not been heard, *'But I hate social workers 'cause they don't listen to you.... what you need in life'*. At times he gave up trying to communicate his feelings because he did not feel they would be listened to, *'I used to cry every night... I used to keep quiet about it. I didn't want to say nothing to my social worker because she doesn't listen to me'*. He felt that decisions were often made according to what professionals thought was best and that they did not take his opinion into account, *'She says [social worker] she did it for my benefit but deep down in my life it didn't work out that way'*. This suggests that Darren felt very alone at times, with no one to talk to and no one to care for him.

Difficulty trusting others

His move out of home had forced Darren to depend on others for support, but as a result of being frequently and repeatedly let down by those around him, he now found it difficult to trust other people, *'Don't depend on people. Don't put your trust in social workers'*.

- *Broken promises*

One factor which appeared to contribute to Darren's reluctance to trust others was the repeated experience of others breaking the promises they had made him. In particular he felt professionals did this, *'They make promises that they don't keep... Why should I be the one waiting in for a person if they're not going to ring you and tell you that they're not coming at*

this time?’ However, friends did this also, *‘Friendships they’re a bit down sometimes, and sometimes they make promises to keep in contact and they don’t’.*

- *Feeling taken advantage of*

Darren also felt taken advantage of by others, often by friends or girlfriends who he had trusted and who had then let him down. *‘They used to take me for a ride, take money off me and everything’.* He felt that at times he was taken advantage of because of his learning disability, *‘I’m not meaning to be rude but how many people just take liberties out of people what’s got learning disabilities?’.*

- *Not feeling cared for*

All the experiences described above appeared to make Darren feel that those around him did not care about him, *‘You have to make promises what you’re going to keep. There’s no point saying oh next week I’m going to see Darren at his flat and then not turn up. That person’s going to be thinking well they don’t care’.*

At times, Darren appeared to attribute feeling uncared for to his learning disability, *‘people with learning disabilities... they’re not bothered about them’.* However, at other times, he appeared to blame himself for these experiences. For example, when talking about one social worker he said, *‘she got fed up of me’* and when his mother suggested he move out he described this as being, *‘a bit personal really’.* Feeling so uncared for by those around him may well have left Darren lacking in self-esteem.

Feeling angry, frustrated and disappointed

Darren described feelings of anger at the lack of care and support he received during his residential transitions, *‘I was quite cross with it. I was pissed off’.* He also expressed sadness and frustration at not always getting the help he needed to be independent, *‘I wish sometimes I had a good life you know. Doing things... you know... being more independent, standing up with my own two feet. I’m doing that but they just need to make an effort more’.* Darren also spoke of being disappointed with others around his needs not being heard or met, *‘I was disappointed with it but I decided to do what they wanted me to do’.* However, he also spoke of being disappointed with himself, *‘I wish I knew all my money properly more than depending on other people to count my money up for me... I feel disappointed with myself’.*

Theme Three: Loss and Rejection

Darren talked about experiencing multiple losses in terms of both personal and professional relationships. Many of these losses were experienced as rejections or abandonments, reinforcing his feelings of loneliness and not being wanted or cared for.

Loss of family

Darren had experienced several losses in terms of his family. His father had died, *'I was disappointed with my Dad leaving me like this'*, and his mother had asked him to move out, *'Well she wanted me to move out, but I didn't really want to go'*. In addition to this his sister, to whom he had been very close growing up, now had a family of her own and no longer spent time with him, *'We used to go more places. But now we don't go nowhere 'cause she has got a child'*. The words used in these statements appear to suggest a sense of having been abandoned, rejected or replaced in some way and Darren spoke of these events with great sadness. Although Darren did not express any anger towards his family, he did talk more generally about parents letting their children down which seemed to suggest an unspoken personal hurt, *'They should do better. Make sure your kids are with you more than behind you, you know'*.

Loss of friends and girlfriends

Darren had also experienced losses within his friendships and romantic relationships. Friends had not kept in touch as described above and girlfriends had repeatedly rejected him, *'I ended up falling in love with different people... and then I got my heart broken and then I moved on'*. Again these experiences suggested a series of rejections and abandonments, and may well have left Darren feeling alone and unlovable.

Loss of professional relationships

Finally, Darren had also felt abandoned by his social worker who had not informed him that he was leaving, *'Cause he made promises that he would never disappear, he will always be my social worker, but he didn't keep his promises'*. He went on to say, *'He didn't keep in contact with me... he should be more able to keep in contact with you and say well I'm not your social worker anymore, someone else is'*. This highlights the strong attachments that can be formed with professionals and the importance of continuity of care and contact.

Theme Four: Not getting the right kind of care

Darren spoke at great length and with passion about the care he received from professionals and his family and the ways in which it could be improved. He talked about the importance of receiving balanced support, of being encouraged and of needing to feel respected.

Providing balanced support

- *Laidback vs. Bossy*

Darren spoke of those who had supported him as often being either too *'laidback'* or too *'bossy'*. When people were too laidback he often felt like he had to do everything on his own, *'But the staff were too laidback... you know you do your own thing, you do your own shopping'*. However, on the other extreme, when people were too bossy he felt unable to do anything for himself, *'She was a bit bossy. She wanted to do everything for me, but I didn't like that. I wanted to do things for myself and be independent'*.

- *Teaching*

It seemed that the kind of support Darren desired was somewhere in between being laidback and bossy, more of an educational support, *'Being independent means they show you how to do it first then you do it afterwards. Not them sitting back and saying nothing to you'*. He described how people should be given a chance to do something and be offered support only if they are struggling, *'You're not telling them what to do, you just let them do it and then watch them do it and then if they do it wrong you tell them they're doing it wrong'*.

- *Need for boundaries*

While Darren did not appreciate people being bossy he did recognise the need for boundaries. For example, when talking about his mother he said, *'I wish she was more stricter... showing more discipline more than sitting back and saying nothing'*. It seemed that Darren needed to have boundaries in place, perhaps because this made him feel that people were concerned about him resulting in him feeling cared for and loved.

- *Timing*

Finally, Darren also spoke of needing support to be offered at the right time, and how support often came when it was not needed, *'The only time they would come and see you was when you don't need them'*.

Not feeling good enough

- *Feeling criticised*

It seemed that Darren was often left feeling like he couldn't get things right. Even when he felt things were going well and he was succeeding, people would point out his mistakes, *'I picked things up fast you know like paying the bills... I was cool with that. But they sent round my social worker got involved with it and then she goes that she can't be helping him like that'*. He also at times felt ridiculed for not knowing how to do things, *'They used to say to us you ought to know this... they're laughing at us because we don't know nothing'*.

- *Being expected to fail*

At times Darren reported feeling like others did not expect him to succeed at things, *'She [my mother] thought I would have failed by now but I haven't failed'*. This is also reflected in the way in which he was sent to live with a support worker rather than being supported to live independently as he desired.

Needing to feel respected and equal

There was a strong sense of Darren not feeling respected by those around him. For example, he talked about people needing better manners, *'Some people haven't got manners to ring people'*. He particularly liked his current providers of support as they kept their promises, *'They're great because they keep their promises what they want you to do. They keep their promises'*. He also felt more in control of his current support, *'And if you don't need them on that day you just ring them and say I don't need you this week, can you come next week'*, which seemed to imply a mutual respect, *'So it's a two way thing'*.

Summary

For Darren, the move out of the family home had exposed him to many negative experiences including loss, rejection and powerlessness. This had impacted upon his self esteem and his relationships with others. Such experiences also appeared to have occurred in other areas of his life such as with friends and girlfriends. Whether his residential transitions were characteristic of a generally difficult life or whether they represented particularly significant challenges that had a unique impact is difficult to know.

Table 6: Participant Three: Liam

| 1. Move as an opportunity | 2. Limits to control | 3. Struggle |
|--|---|---|
| <p data-bbox="300 628 562 655"><i>Increase in autonomy</i></p> <ul data-bbox="300 663 685 730" style="list-style-type: none"> <li data-bbox="300 663 685 691">• <i>Wanting to be independent</i> <li data-bbox="300 699 685 730">• <i>Making his own decisions</i> | <p data-bbox="864 628 1236 655"><i>Pushed out of the family home</i></p> <p data-bbox="864 699 1151 730"><i>Lack of informed choice</i></p> | <p data-bbox="1429 628 1733 655"><i>Interpersonal difficulties</i></p> <p data-bbox="1429 699 1675 730"><i>Wanting to do more</i></p> |
| <p data-bbox="300 775 573 802"><i>Increase in friendships</i></p> | | |
| <p data-bbox="300 847 577 874"><i>Feeling well supported</i></p> | | |

3.3 Participant Three: Liam

Liam was a Black British man who had experienced multiple moves since leaving the family home. He too was in a supported living network and lived in a flat on his own. Liam found the interview difficult and at times gave very short answers. Although he reported being glad that he had taken part, he often appeared to be anxious and seemed to find the interview quite intense. In order to make him more comfortable it was agreed that his interview would be carried out on two separate occasions.

Theme One: Move as an Opportunity

For Liam, the move out of the family home appeared to have led to an increase in opportunities, both in terms of autonomy and friendships. These opportunities had been achieved partly because of the support he had received throughout the move.

Increase in autonomy

- *Wanting to be independent*

Liam frequently spoke of desiring independence. For him, the meaning of independence seemed to reflect several things including living on his own, *'I just wanted to get my own place... 'Cause you're by yourself innit?'*, looking after himself, *'Do your own shopping and that. Do your own laundry'*, and having the freedom to go anywhere he wanted, *'Independent as well by yourself... travel everywhere'*.

Liam was encouraged to be independent by the hostels he stayed in, *'they tried to move you on into your own place.... So you could be independent'*. The hostels expected Liam to look after himself to some extent, *'you have to do cleaning and things... do your own shopping, use the washing machine'*, but he found this helpful rather than unsupportive. Perhaps this is because his goals matched those of the professionals helping him.

- *Making his own decisions*

Liam also spoke about how living independently meant that he could decide what to do for himself, *'You can do your own thing. You can have your friends round. Family. Friends. You can do your own thing. Play music. Watch telly. Smoke – have a cigarette'*. It seemed that Liam appreciated being in control of his activities and not having others deciding things for him.

Increase in friendships

Liam spoke of having few friends when he lived in the family home, *'No, no I didn't. I didn't have no friends'*. However, moving out appeared to have increased his friendship group. He talked of meeting people in the hostels in which he lived, *'A couple of guys... I made some friends with'* and of one male friend with whom he moved between hostels and remained close to even now. When describing his current social situation he said that, *'Yes, I've got friends'*. Thus, for Liam, the process of moving out of home appeared to provide him with opportunities for friendships that he may not have had if he had stayed with his family.

Feeling well supported

Liam did not appear to have a high level of need and did not report having any great difficulties in the tasks he had to perform once he moved out of home, *'I found it easy'*. When unsure of how to do something he would approach staff and, *'write a list down'* so he could remember what to do. He also had an attitude of sticking things out and seemed aware that things often become easier over time. Of living alone he said it was, *'strange at first, living by yourself. When I first moved in, it was a bit strange but then I got used to it after a while'*.

Liam was pleased with the amount of support he had received and reported that staff in the hostels would *'look after you'* and were *'friendly'*. He talked about staff helping him with difficult tasks, *'Staff would go shopping with us to buy new clothes... sort out your money and that until you move on to get your own place and you can do that yourself'*. He also said they would, *'sort out your bills and that... when you get post they'd look at it with you'*. They would also set rules and boundaries which he seemed to appreciate, *'you had to do stuff when staff tell you. Clean the lounge and everything... hoover the stairs'*.

Theme Two: Limits to Control

Despite his relatively positive experience of transition, Liam did talk about times when his control and choice was limited. This was most apparent when he talked about why he moved out of the family home, and when he described the amount of choice he had had in the transition process.

Pushed out of family home

Liam described conflict with his mother as the main reason for moving out, *'Err, bit of trouble... I didn't get on with my Mum so I moved out'*. When asked how his mother felt about the move he said, *'Umm, not bothered... She said it was better for me'*. Liam described the move as being his decision, but was reluctant to elaborate on the reasons behind it. It seemed

as though he may have felt some pressure from his mother to move out or that he may have felt a little unwanted or pushed out. It was also one of his mother's friends who helped to arrange the move suggesting that his mother had more say in it than he chose to reveal.

Lack of informed choice

Liam's choice and control over his moves appeared to be limited. It was someone else who decided that he should move into a hostel, *'Someone else did'*, and he was not given the opportunity to visit the hostel first, *'No I just moved in'*. When he moved into his own flat, he said he chose it himself and was able to view it beforehand, *'Yes I did. They showed me round the flat. They showed me it'*. However, he only actually saw one flat, *'No, just that one. I picked that one'*, raising the issue of how informed his decision really was.

Theme Three: Struggle

Although Liam reported finding practical tasks such as washing and cleaning relatively easy, at times he appeared to struggle. This struggle seemed to happen in relation to his interpersonal skills and planning skills, and as a result impacted on his friendships and activities.

Interpersonal difficulties

In addition to not getting on with his mother when he lived at home, Liam also appeared to have experienced some interpersonal conflicts with others. For example, he had stopped going to college due to problems with the students there, *'Er... I had a bit of trouble with the other students so I left'*. This highlights not only a difficulty getting on with other people but also the tendency to withdraw from or avoid difficult situations as a means of coping. Liam was also the only participant who appeared anxious during the interview, often finding it difficult to elaborate on his answers and articulate his thoughts and feelings.

Wanting to do more

Liam appeared to enjoy being active. In addition to the hobbies already described he talked about enjoying, *'Going out... different places... town, restaurants..'*, and being a member of different groups and organisations. However, he also spoke of not having enough to do since living on his own, *'Bored. No I need something to do'*. When asked what he would like to spend his time doing he seemed unsure, perhaps indicating a lack of knowledge or information about what was available or possible. However, when probed further he said that he would like to, *'Get a push bike so I could ride everywhere. I like bikes as well'*. This was not however

something he had shared with his support workers and thus had not been achieved. This difficulty in thinking of activities and formulating how to put ideas into practice meant that he was left feeling bored and frustrated with his everyday life.

Summary

Liam had a relatively positive experience of moving out of the family home in which he felt well supported and at least partially in control. His move had also provided him with increased opportunities for friendships and autonomy. Despite this, Liam did struggle with people and tasks and at times was unable to realise his goals.

Table 7: Participant Four - Jack

| 1. Awareness of difference | 2. Wanting to be seen as a man | 3. Empowerment | 4. Feeling vulnerable |
|---|---|---|---|
| <p><i>Impact of labels</i></p> <ul style="list-style-type: none"> • <i>Having a disability</i> • <i>Being Black African</i> • <i>Recognising and resisting discrimination</i> | <p><i>Wanting to be seen as a man</i></p> <ul style="list-style-type: none"> • <i>Being perceived as a child</i> • <i>Wanting to be independent</i> • <i>Having paid employment</i> | <p><i>Determination</i></p> <ul style="list-style-type: none"> • <i>Encouraged by others to try</i> • <i>Move as a challenge leading to new skills</i> <p><i>Feeling accepted and valued</i></p> <ul style="list-style-type: none"> • <i>Accepted by peers</i> • <i>Priorities heard</i> • <i>Experiences listened to and valued</i> <p><i>Move as a planned choice</i></p> | <p><i>The world outside as a dangerous place</i></p> <p><i>Being on his own</i></p> |

3.4 Participant Four: Jack

Jack was a Black African man who was the only participant to have planned the move out of the family home himself. He had had a largely positive experience of moving and had stayed in his first flat in a supported living network. He seemed to enjoy the interview, although due to some speech difficulties he was not always able to elaborate on his answers at length and requested a short break halfway through.

Theme One: Awareness of Difference

In the interview, Jack talked about the labels used to describe his disability and ethnicity and the way in which they made him different to the majority.

Impact of labels

- *Having a disability*

Jack described himself several times without being prompted as having a learning disability. These references were often made in the context of talking about his job in which people with learning disabilities are employed to talk about their experiences, *'tell everybody about my past experiences of disability person', 'and it organises people who've umm... got umm... disability'*. Thus having a learning disability seemed to be an acknowledged and important part of Jack's identity, but also something that he was aware made him different from others.

- *Being Black African*

Jack described himself as being Black African and acknowledged some difference between his country of origin and the UK, *'Well culture wise it's not the same as over here'*, He did not however appear to feel that his ethnicity had particularly influenced his life or transition in any way. He did not appear to have a strong affiliation to either his country of origin or the UK, choosing for example to support a European national football team, *'No it's a France international team. I like France as well'*.

- *Recognising and resisting discrimination*

There was some recognition by Jack that the labels above related to people who were disadvantaged in some way. When talking about people with learning disabilities, he described how his organisation spoke up for them, *'And we umm... campaign for umm... for people with ... people who've umm.... disabilities'*. When talking about his country of origin in Africa he mentioned their social deprivation, *'Well they umm... poverty and... that's bad'*.

Theme Two: Wanting To Be Seen as a Man

Jack spoke in the interview of wanting to be mature and be seen as a man, perhaps partly because of the way he was treated in the family home. For Jack, being a man appeared to involve moving out of home, being independent and having a paid job.

- *Being perceived as a child*

When living in the family home, it appeared that Jack was often treated in quite a child-like way even when he was in his twenties. For example, Jack said, *'if I wanted to go out I asked Mum first and she said yes I can go out'*, and that this made him feel, *'silly sometimes really'*. It is possible that this sense of being treated like a child was compounded by the fact that his younger brother had moved out of the home and started a family before him. Jack's motivation for moving out was to be mature and start *'acting like a man'*.

- *Wanting to be independent*

When Jack talked about his goals he said, *'Well I wanted my own place. A home of my own really, yeah, and to be independent really'*. When asked what being independent meant to him, Jack responded, *'Well it means that if you want a ... say like... if you are independent you can go out any time you want'*. It seemed that for Jack, being independent meant having his own home, being in control of his own decisions and not being told what to do, *'in my own flat I can just chuck my keys in any corner that I want... I can do what I want'*.

- *Having paid employment*

Being paid for his work also seemed very important to Jack, perhaps giving him a sense of self-worth, *'I'm paid as well and I get paid every time I do training, I get paid after I've done it'*. The meaning of the role he had in his employment is commented on in the next theme.

Theme Three: Empowerment

Jack seemed to have a high sense of self worth. This seemed partly due to others encouraging him to be determined and try hard at tasks, and partly due to feeling accepted and valued by others. The fact that his experience of residential transition had been a positive and successful one also appeared to have contributed to his sense of self-worth.

Determination

Jack appeared to be quite determined to try things; even when he knew things would be difficult he did not appear to be put off. This was reflected even in the words he chose to use, *'Yeah well [name of employment] is an... organisation... I can't say that word... I try but I never can say'*.

- *Encouraged by others to try*

This self-determination in part seemed to come from those around him offering him support and encouragement. When living with his family Jack said that, *'Any time I was angry or upset the family were there... Say everything is going to be alright'*. They also seemed to offer him a model of coping which was about sticking with things and not giving up or running away. For example, when there were frequent attempts to break into the family home, the family refused to leave until eventually the aggressors themselves moved on, *'No but it is ok now because they've all disappeared from there. It's safe, so quiet'*. When Jack decided to move out, people around him encouraged him and gave him advice such as, *'enjoy it'*.

- *Move as a challenge leading to new skills*

Although Jack's decision to move out of the family home did make him feel sad and worried, it also led to the development of new skills. Jack talked about how he now felt able to accomplish household tasks, *'Cooking's alright... I umm pay all my bills... Yeah I do all the cleaning now'*. He also reported feeling, *'A bit more confident...about going out... in the evening'*.

Feeling accepted and valued

- *Accepted by peers*

Moving out had provided Jack with more opportunities to develop friendships. He reported having good relationships with others and talked about his friendships, *'Yeah, and I like to go out with my friends and have fun'*. He had both Black African friends and also White friends, *'Well, it's more umm... umm... yeah it's mostly White friends I have mostly'*, indicating that he had been accepted by both people of his own ethnic group as well as those from the White majority. He also reported never having been the victim of any racist abuse, *'I've never had a hate crime experience'*.

- *Priorities heard*

Jack's main priority in moving out was to remain close to his mother's house. This was ultimately why he chose the flat he did, *'It was because it was close to my Mum's house really. And any other flats were further away from my Mum's you know'*. Having this need met allowed him to have a continued relationship with his mother and carry on with the things he used to do with her, *'[We do] stuff I used to do before when I was in the house with her'*.

- *Experiences listened to and valued*

Not only were Jack's priorities in moving listened to, his employment also gave him the opportunity to feel heard, *'And what I do is, tell everybody about my past experiences of*

disability person, of hate crime and umm... sufferers of hate crime and we train people on that'. As mentioned earlier, this employment was paid which perhaps gave Jack the sense that not only were his opinions worth listening to, they were also worth paying for.

Move as a planned choice

The decision to move out of the family home was one that Jack made himself, *'It was my decision really'*. It was also a decision that Jack was able to make in his own time without feeling rushed. When asked why he waited to move out rather than leave in his late teens he replied, *'Well at 18 or 19 I was... I was immature at that age. I was immature. Immature age really'*. The fact that Jack made this decision himself would indicate that he did not feel a sense of rejection or abandonment that other participants inferred. It is likely therefore that this contributed to his positive self image.

Theme Four: Feeling Vulnerable

Although Jack's move out of the family home was his own decision, he still spoke of feeling worried and sad about aspects of the move.

The outside world as a dangerous place

Jack spoke of his anxieties regarding living on his own. Often these anxieties centred around feeling unsafe when he left his flat, *'Yes you're umm... vulnerable... vulnerable more... people can take advantage of you more'*. Perhaps living on his own meant that he no longer had anyone else to protect him. Feeling vulnerable seemed to be a preoccupation, so much so that he would seek advice from those around him as to how to keep safe. He told me he followed advice such as, *'if I'm out in the evening, always walk where there's light.... always walk in the light where people can see me so I don't get attacked'*.

It is possible that these fears stemmed from his experience of living in the family home when there were frequent attempts to burgle his house, *'they always tried to break in. But they didn't manage to do it... so many times they tried to break in but every time failed, every time'*. These experiences made Jack feel angry, and may have led him to believe that the world outside his home could be dangerous.

Being on his own

Jack also reported feeling sad about no longer having his family with him, *'Out of home made me upset... being on my own'*. As described earlier, Jack was given a lot of emotional support by his family. Interestingly however, Jack had few friends when living with his family, *'I*

used to go round on my own, I didn't bother with friends really', something which seemed to have changed since living on his own. Jack talked about having far more friends now and feeling 'happy and friendly'. It is possible that his family substituted as his friends when he lived with them, for example he used to do a lot of things with his brother such as, 'going into town, played pool... the cinema'.

Summary

Jack's key role in planning his move out of the family home, along with the empowering support given to him during his residential transition appeared to have positively impacted on his experiences. He spoke of feeling in control, feeling accepted rather than rejected, and of becoming a mature man. Interestingly, even Jack described feeling anxious about the move and having some concerns about living on his own; this highlights how mixed emotions can be a normal and expected part of a residential transition.

Table 8: Participant Five - Michael

| 1. Rejection | 2. Repeated and enforced Loss | 3. Experience of support |
|----------------------------------|---|--|
| <i>Discriminated against</i> | <i>Multiple losses</i> <ul style="list-style-type: none"> • <i>Loss of family and friends</i> • <i>Loss of community</i> | <i>Unsuccessful help seeking</i> |
| <i>Pushed out</i> | | <i>Inappropriately caring for others</i> |
| <i>Left behind</i> | <i>Powerlessness/ Lack of control</i> <ul style="list-style-type: none"> • <i>Seeking predictability</i> • <i>Searching for explanations</i> | |
| 4. Favourable comparisons | | 5. Hopes and fears for the future |
| <i>4.1 Living independently</i> | | <i>5. 1 A new future</i> |
| <i>4.2 Having a job</i> | | <i>5. 2 Taking risks</i> |
| | | <i>5.3 Valuing independence</i> |

3.5. Participant Five: Michael

Michael was a Caribbean man who had moved out of the family home into care when he was 18 and had subsequently lived in various hostels and flats. He currently lived with his partner in a supported living network. Like Darren, Michael was very passionate throughout the interview and talked at length with little need for prompts. He appeared at ease and reported finding the interview enjoyable.

Theme One: Rejection

Michael spoke about many experiences of rejection throughout his interview. These experiences involved being discriminated against by others because of his ethnicity, feeling pushed out of the family home, and being left behind as his family moved on to other places. All of these experiences appeared to have left Michael feeling rejected and unwanted.

Discriminated against

Michael talked about having been discriminated against due to his ethnicity throughout his life, so much so that it had almost become something he expected, *'Well there's a lot of people on the street that don't like my colour but... that's how it goes... but I just take it as offence. I don't take it any other way'*. He often felt like he didn't fit in and described being particularly targeted when he was in school and in care. At school he talked about how he felt visibly different, *'It were all sort of White and I was coloured but I didn't like it like that... I felt that I looked a bit strange because the way they were hanging'*, and how his attempts for friendship were rejected and how, *'I got offended for my colour... I tried to mix into it... I tried to get into conversation with the people there but there was no chance'*. Michael talked about feeling confused as to why he was treated this way; when describing living in care he said, *'the person says you can't come here, you're not allowed to come in... I says why not? What's the difference? I'm dark and they're White and what's the difference?'*. Interestingly he did not speak about being discriminated against because of his learning disability; instead he attributed the way he was treated only to his ethnicity.

Pushed out

Michael described his experience of leaving home as something that he was forced into due to family conflict, *'They started arguing and so I had to go into care'*. He did not want to leave his family home and felt that he was rushed into it before he was ready, *'they wanted me to go but I didn't want to go straight away 'cause there was nowt for me to go for... I didn't want to go anywhere. I didn't want to leave home and it was really sad for me to go'*. He felt

pushed into leaving not only by his family but also by professionals, *'The person who was supposed to find me somewhere to stay said you can't stay at home any longer. You're supposed to be independent yourself'*. The concept of independence was therefore forced upon Michael at a time when he did not feel ready for it or even sure that it was something that he wanted. The way in which Michael talked about moving out suggested a feeling of being unwanted but also a sense of powerlessness, of being forced into doing something he desperately did not want to do.

Left behind

Despite being the oldest, Michael was the last to leave the family home as all his siblings had moved out before he did. In addition to this, his parents ultimately left him too, deciding to return to the Caribbean while Michael remained in England. This meant that he was no longer able to see his parents, *'I don't see my family now. 'Cause they're not in this country so I don't see them... In Caribbean, they live over there now... That's why I don't see them now'*. There was a sense that even before his parents returned to the Caribbean, they did not spend a lot of time with Michael, preferring instead to do things on their own, *'they do their own thing... they do what they want to do, they got their own freedom'*. These experiences may have led to Michael feeling abandoned by his family.

Theme Two: Repeated and Enforced Loss

Michael had frequently experienced loss, often because of decisions made by others against his will. The losses themselves were a source of sadness and frustration for Michael, and the powerlessness he felt in relation to them left him seeking a more predictable life and wanting to understand what had happened to him.

Multiple Losses

As he talked, it became apparent that the move out of the family home represented a series of losses for Michael. Moving out meant not only the loss of his home and day to day life but also the loss of his remaining family, friends and community.

- *Loss of family and friends*

Michael had already been left behind by his siblings before the move, but the move itself took him away from his remaining family and friends. He spoke with sadness about having to leave his friends behind, *'I used to get on with them but since I moved from there it's just I've lost everyone... Since I've moved from there I've lost all my friends from there'*. Michael also talked about the loss of his dog, something that he found very difficult, *'I used to have a*

dog as well at one time but... I had to give that away. I was really gutted. 'Cause that dog was really good for me and I had to give it away because I couldn't take it where I was going'. He spoke of this with great sadness and frustration and with a sense of injustice that what had been promised to him had been later refused, 'I was really upset about it. But they said you could take your pets with you but they wouldn't allow it for some reason'. Michael had gone on to experience further losses in his life, including the loss of his wife who passed away. This had left him with some fear and anxiety about taking further risks in case he ended up experiencing further loss. This is explored in more depth in the fifth theme.

- *Loss of Caribbean community*

Throughout the interview, Michael talked repeatedly about his love of Caribbean food and events. He felt dissatisfied with the location of his current flat as it was not in an African Caribbean area and it therefore meant that he could not get to certain shops and events. Michael was frustrated that he was unable to get the food he wanted in the area that he lived, *'You haven't got the sort of food you've got in [African Caribbean area]. If you go to [African Caribbean area] you see all the Caribbean shops but you don't see them round here. I think it's really poor round here really... I'm just really gutted... I like to see the food actually being made. There's no chance of that. Not from where I am anyway'*. Michael knew other people who could access the food he wanted; these comparisons made him more aware of what he was missing out on, *'I know a person who comes from the Caribbean.... and she gets a lot of stuff from Caribbean thingys. Where she lives, she can get all that and I can't get that'*.

Michael also spoke with fondness of the Caribbean events he used to go to and how he could no longer go to these, *'On certain days they'd have a carnival up there and now that's going I can't... I can't get over there but... just it's hard... it's totally outrageous. There are lots of other things you can do up there. But when it's a carnival day it's a lovely time to go up. I used to go up. I loved to go up. Every time it was a carnival day I used to go up. You used to get changed up in it, dressed up in it and all sorts. It was lovely'*. Again this left Michael feeling sad and frustrated about the things he was unable to do.

Powerlessness/ Lack of control

Many of the events in Michael's life had happened against his will, suggesting a sense of powerlessness and lack of control. Not only had Michael been pushed into moving out of the family home, he had also been moved from place to place repeatedly, often with little choice as to where he went, *'I had to move from there 'cause there was no choice to go... to move from there... I had to go from there', 'That's where I've been moved'*.

- *Seeking predictability*

Perhaps because of this powerlessness, Michael sometimes talked about desiring predictability, *'I just want to see what were going to happen in life but you can't always plan'*. He described that when he was living in the hostel, he liked to know what he would be doing each day and constructed a chart so that he could follow a daily routine, *'I used to write down on days what I had to do. Each day so I knew what was going on'*. Knowing what lay ahead of him each day gave him a sense of security and safety.

- *Searching for explanations*

Michael often talked about feeling confused about the things that had happened to him. He did this frequently when talking about the discrimination he had suffered, *'Well I couldn't mix with the people there because they were all White. I wonder why? I wanted to know why I couldn't mix'*. He also expressed confusion when talking about his parent's arguments, *'They didn't get on with each other for some reason'*. The world therefore appeared to be a confusing place for Michael, and a place that he was trying to make sense of.

Theme Three: Experience of Support

Michael spoke of the support he had received throughout his life. When living in the family home he spoke of having a small amount of support which he felt was just right, *'When I was at home I used to have...er... I used to have a little bit of... that support but... just a little support I wanted'*. He also reported being satisfied by the level of support he received in his current flat. This seemed to be because the level of support offered matched his level of need.

His main experience of struggling with support came from living in the hostel, in which he often felt inconsistently supported by staff, *'They were helpful in some ways but not as you would think. They wanted to be helpful, they wanted to do all that and what it is they'd help you in one way and then another way they wouldn't help you'*. He often felt left on his own to do things, *'you had to do it all yourself'*, making him feel uncared for.

Unsuccessful help seeking

Michael was able to ask for help, *'I asked the staff to give me a bit of support to see what I can get through'*. However, he often found it difficult to get the staff in the hostel to understand what he wanted and so had to use a chart through which to communicate, *'No they couldn't speak my language unless I had a chart to tell them what I wanted'*. He also reported that many of his requests for help were rejected, *'When you ask for things like that they usually say you can't have it'*.

Inappropriately caring for others

Michael appeared to be one of the more able residents in the hostel and as a consequence he often found himself inappropriately caring for others because staff were not available, *'He couldn't get about so I used to help him get about and he used to be in a wheelchair and he... but the staff wasn't doing their job. Staff never came in until a certain time so I had to end up helping him, getting dressed, cleaning and...doing all that... staff were supposed to do that... by the time they come in at a certain time it was already done. It was too late because I already did it'*. This experience and the injustice of it made Michael feel hugely frustrated.

Theme Four: Favourable Comparisons

When talking about his current life, Michael often talked about himself in relation to other people that he identified with. These comparisons often left him feeling proud of himself, as he felt he had achieved things that others hadn't.

Living independently

Despite a difficult move out of the family home, Michael now felt lucky to be living independently. He talked about certain friends who had not been able to do this and how he felt sorry for them, *'I feel sorry for people who live at home. My friend, he's been at home for so long and he wants to move. I mean he not wants to move, he wants to get his own place but I keep giving him support to move out but there's no chance of it'*. Often such friends were staying at home in order to care for parents, highlighting a mutual dependency which made it difficult for them to leave. Michael also talked about people wanting to live with a partner like he did. *'Well I live at home with my partner and they want to do the same'*.

Having a job

Michael talked at length about his job and how other people with learning disabilities wanted to join his organisation. He talked about how such people wanted to be like him, *'They want to do the stuff that we're doing'*, and about his role of training others to be more independent, *'We're trying to make them come our sort of way to get more independent to go out and stuff'*. He also talked about other people having fewer opportunities than him to get out and do things, *'We go to these sort of meetings and all sorts like that. So people who are like that, they don't get the chance to go to meetings and stuff like that, they can't get out that way'*. Michael seemed to feel quite lucky in relation to these people and when he talked about his job and abilities he sounded like a role model that others looked up to and respected.

Theme Five: Hopes and Fears for the Future

Michael spoke about his dreams and fears about the future, and what more he wanted to achieve.

A new future

When reflecting on the last few years of his life and the series of transitions he had made he said, *'It's been a turnover for me really... 'til now I've come to a new future. I've come to a new partner'*. Although he wished to move back to the African Caribbean community one day, overall he seemed positive about his current situation, *'When you've been all over the place then you just come to a new start, you feel settled... I feel settled now. I feel really good'*.

Taking risks

Michael talked about the frustration of not knowing what was going to happen in his future, *'I've always found that the future... I don't know what's coming in my future because I haven't down owt yet'*. This meant that he had to make choices that could feel risky as he could get hurt. For example when talking about his new marriage, he spoke of being fearful of having to endure another loss but feeling like he should take the chance and see if he could be happy, *'I was going to stay how I was but I wasn't going to go through that again. But I thought, oh, I'll get married again, see if it works'*.

Valuing independence

Although the goal of independence was initially imposed upon him by others, Michael talked about how he now felt happy to be independent. To him independence meant that, *'you can do what you want... go where you want, come in when you want, do what you want'*. He acknowledged that he never had this when he lived in the family home, *'I didn't used to do that when I was at my Mum's. I didn't get none of that. At a certain time you had to be in, especially on a school day. There's more to do what you want now than you could do when you was at home'*.

Summary

Michael had experienced repeated transitions and losses, often against his will, which had sometimes left him feeling powerless, rejected and unsupported. However, he had managed to build a meaningful life for himself and his partner. He coped with his anxiety about the unpredictability of life by trying to establish routines and by trying to make sense of his experiences.

Table 9: Participant Six - Daniel

| 1. Not fitting in | 2. Feeling unwanted | 3. Change in relationships |
|---|--|---|
| <p><i>Of a different ethnicity</i></p> <ul style="list-style-type: none"> • <i>Different to the White majority</i> • <i>Different to his country of origin</i> • <i>Not being Caribbean</i> | <p><i>Feeling like a burden</i></p> <ul style="list-style-type: none"> • <i>In family home</i> <p><i>Feeling unwelcome</i></p> <ul style="list-style-type: none"> • <i>In residential home</i> | <p><i>Loss of family</i></p> |
| <p><i>Of a different age</i></p> <ul style="list-style-type: none"> • <i>To other residents</i> | | |
| | <p>4. Loss of autonomy</p> | <p>5. Feeling cared for by staff</p> |
| | <p><i>Restrictions on freedom</i></p> | <p><i>Rules and boundaries</i></p> |
| | <p><i>Restrictions on activities</i></p> | <p><i>Feeling heard</i></p> |
| | | <p><i>Good availability of support</i></p> |

3.6 Participant Six: Daniel

Daniel was a Black British man who lived in a group residential home with four other service users. His mother had suggested he move out of the family home several years earlier and he was now living in his second home after some difficulties in the first one. He reported enjoying the interview but was at times a little distracted, wanting to tell me about his hobbies and ask me questions about myself.

Theme One: Not Fitting In

Daniel spoke about many social and ethnic groups when talking about his past and present housing, but did not seem to feel as though he fully belonged to any. At times this left him feeling in the way, different, and rejected by others.

Of a different ethnicity

- *Different to the White majority*

Daniel spoke of being '*Black British*' and aligned himself with Britain, '*I was born here, I'm a British citizen*'. However, other people saw his ethnicity as making him different, and when in his first residential home he had been discriminated against by another resident because of his colour, '*And he said to me once that I was a Black bastard and I should go back to [name of area] where I've come from*'. Thus, other people made him feel like he was different and that he did not fit in.

- *Different to his country of origin*

Daniel had visited his family's country of origin once for his father's funeral, '*I've been once when they went to bury my Dad when he died*'. He had witnessed some traditional African customs during his stay, '*They had lots of cultural dances and stuff*', but had not felt included in such events, '*But there was a man... there was a man that whacked me with a broom sometimes and it hurt. I think I was in the way or something but it was quite hard*'. Again he was made to feel different to those around him, and found it difficult to fit in.

- *Not being Caribbean*

Daniel was the only participant who openly differentiated between African and Caribbean people. He often talked about West Indian or Rastafarian people who formed a large part of the community in which he lived when he was growing up in the family home, '*They have a lot of... Do you know what Rastafarians are? They have a lot of them there as well on the street, and lot of Jamaican people as well*'. He spoke of these people forming a close community, yet did not appear to feel included in their group, '*They used to play, you know*

like reggae on the street. And people used to gather round and they used to listen to it. They used to have like sound systems and they used to play their music really loud. ... on the street... It drew everyone together, they were all listening to it'.

Of a different age

- *To other residents*

When talking about both his current and previous residential home, Daniel spoke of feeling different in terms of his age. His first home did have a mix of ages, *'Twelve people were living there, they were all men and ladies. But they were all elderly people and some young people as well. Some of them were young, around my age'* but his current home did not, *'There's four elderly people where I am living now'*. When speaking of his ideal home he talked about wanting to live with young people aged sixteen to thirty and that this would make him happy.

Theme Two: Feeling Unwanted

Daniel's experience of having to move out of the family home and live in residential care had made him feel unwanted by the people he lived with.

Feeling like a burden

- *In family home*

Daniel found it difficult to talk about the reasons why he moved out of the family home, and when this was explored in the interview he became quiet. He took ownership of the decision to move but when he was prompted further, he said he had been happy in the family home and that in fact it was his mother who had suggested he move out, *'Well it was to give my Mum a break... she just thought it would be better for me to move somewhere else'*. When he said this last sentence he raised his voice and seemed quite cross which gave some indication as to how hurt he had been by his mother wanting him to leave. The fact that his mother felt like she needed a break from Daniel suggests that she had seen him as too much work, which may well have left him feeling like a burden rather than a wanted and valued member of the family.

Feeling unwelcome

- *In residential home*

The incident of racism in his first residential home had left Daniel feeling unwelcome by the resident involved, *'He wanted to do rid of me 'cause he didn't like me... And also he kicked me as well'*. This had upset him so much that it became one of the main reasons for his move to his current care home, *'And because of the incident that happened, the guy saying something to me...That's why I moved from [name of area] to where I am now'*. Being made to feel unwelcome was something that he understandably found difficult to tolerate.

Theme Three: Changes in Relationships

Loss of family

Daniel had experienced the loss of several family members in his life. His father had died several years ago, and Daniel still thought about him. When he came to the interview he brought a picture of his father lying in his coffin, *'This picture is of my Dad when he died'*. He also brought pictures of his siblings and mother. Despite being the oldest sibling, by the time it came for him to move, Daniel was the only child left in the house as they had all *'left already'*. He had therefore seen the departure of not only his father, but his siblings too. Finally, he experienced the loss and rejection of his mother. This was made more difficult by the fact that the first residential home he was placed in was in another city, making visits hard. Although his mother did visit him often, he was not able to visit the family home when he wanted, *'Yeah, not often.... because I didn't have time'*. His reason for moving to his second residential home, other than to get away from another resident, was to be closer to his mother who he missed, *'Cause I thought where I'm living now would be much nearer to where my Mum's house is'*. Now, being closer to his mother meant that he had a little more control over when he could contact her, *'She sees me... I just see her now and again. I ring her on my mobile phone whenever I want to'*.

Theme Four: Loss of Autonomy

For Daniel, the move out of the family home appeared to represent a loss of autonomy rather than an opportunity to gain independence and control. This seemed to be because he had moved into a residential group home in which there were restrictions on his freedom and activities.

Restrictions on freedom

At times, Daniel described a loss of freedom since moving out of the family home. It seemed that the staff were concerned about Daniel's safety and didn't like him to go out alone, *'They said to me once that I shouldn't go to the shop as I might get run over. I told them that I won't get run over, I look for cars coming. They always used to say that I need to go with someone. I don't know what they mean by that, I shouldn't go on my own'*. This was in contrast to his life in the family home when it seemed he had more freedom to go out whenever he liked, *'No I went on my own... I used to go into town with my friends sometimes or go to their house and watch videos'*. When talking about his ideal house, Daniel appeared to like the idea of having more freedom, describing his ideal daily activities as, *'going into town, getting the bus every day'*.

Restrictions on activities

As Daniel lived with other residents, outings naturally had to be planned in groups according to which staff were available. This meant that Daniel had to compromise on both the activities he wanted to do and the time at which he did them. Even in the interview, Daniel started talking about how he was planning to go and buy some music with a support worker, *'When I finish here, you know that man that you saw that was stood there, the support worker? We're going to HMV later on... we're going to buy some music'*. However at the end of the interview he was told that the support worker had gone home and that he would not be able to go until tomorrow.

In addition to this, the activities that Daniel pursued when he lived with his family, which included going to college and to a walking group, were very different to those he did now. He was often taken out by staff to different places but he did not seem enthused by these things and sighed frequently when asked about them.

Theme Five: Feeling Cared for by Staff

Despite his loss of autonomy and the restrictions placed upon him, Daniel described feeling happy with the support he had received in both his residential homes.

Rules and boundaries

Daniel talked about being told what to do by staff, *'They were ok, they used to tell me do this, do that... like tidy my room'*. However he said that he liked this and found it helpful; perhaps it gave him a sense of being cared for and attended to. There appeared to be a good

balance between staff supporting Daniel in some tasks and encouraging him to do some things on his own, *'Help to wash my clothes... do some things on my own'*.

Feeling heard

When Daniel had difficulties and needed support, he felt that staff listened and acted appropriately. For example, when his fellow resident verbally abused him he said, *'One of the staff saw it and reported it. One of the staff here, I told them about it'*. This seemed to make him feel like he was taken seriously and well attended to.

Good availability of support

As Daniel lived in a residential home, staff support was available at all hours, including at night time, *'They sleep there at night time, they do a night shift there'*.

Summary

Daniel's experiences of residential transitions appeared to be dominated by feelings of difference and being unwelcome. Unlike the other participants, for Daniel the move out of the family home represented a loss of freedom and autonomy, perhaps because of the setting into which he moved. However, this loss of freedom also brought with it a sense of being cared for by the staff who supported him.

Table 10: Group Analysis - Superordinate Themes

| 1. Struggle | 2. Connectedness | 3. Appraisal with emotion |
|--|--|--|
| <p>Powerlessness</p> <ul style="list-style-type: none"> • Limited control • Lack of informed choice • Enforced loss <p>Frustrated by dependency</p> <ul style="list-style-type: none"> • Feeling unsupported/ neglected • Wanting to do more <p>Striving for autonomy</p> <ul style="list-style-type: none"> • Independence and control • Paid employment • Freedom <p>Being empowered</p> <ul style="list-style-type: none"> • Empowering support • Empowering employment | <p>Feeling unwanted</p> <ul style="list-style-type: none"> • Rejected by people close to them • Feeling different from society <p>Seeking acceptance</p> <ul style="list-style-type: none"> • Wanting close relationships • Belonging to a community • Roles and status | <p>Feeling ill equipped to leave home</p> <ul style="list-style-type: none"> • Feeling vulnerable • Limited conflict resolution <p>Hope for the future</p> |

4. Group Analysis

The data from each of the interviews were analysed as a group in order to determine whether there were themes that were common to the participants as a whole. Many of the themes that emerged from the individual analysis were synthesised in this group analysis as they seemed to represent different dimensions of more global superordinate themes. Three superordinate themes emerged; these together with their subthemes are illustrated in Table 10. In this section, each of these superordinate themes will be discussed in turn along with examples of how they reflect the group's experiences.

Again, although much of the data reflected themes specifically relating to the experience of residential transition, some themes also captured experiences in other areas of the participants' lives. Such themes have been included in the group analysis if they appeared particularly important to the group or were considered to provide the reader with a more general understanding and insight into the participants' experiences.

4.1 Superordinate Theme One: Struggle

All the participants described having to deal with a series of challenges throughout their lives. The experience of moving out of home appeared to be one example of a particularly difficult challenge which involved a complex struggle between feeling powerless and having to depend on others, and being empowered to gain autonomy. This sense of struggle also appeared to feature in other areas of participants' lives, but was particularly brought to light through their experience of residential transition.

Powerlessness

Feelings of powerlessness dominated five of the six participants' experiences of their residential transition(s). This powerlessness was talked about in terms of having little control and informed choice over events, and having repeated experience of enforced loss.

- *Limited control*

Out of all the participants, only Jack had decided of his own accord to move out of the family home, with the others reporting moves due to family conflict, bereavement or pressure from relatives. Jack's move was different in that he decided to move out himself because of a desire to feel more independent and mature. As there was no crisis or stress surrounding his decision to move, he appeared to have had more time to plan his move and find a suitable location. He felt his priorities were listened to and heard, and that he had choice and control over where he moved. He was able to find a flat close to his mother's house, enabling him to continue his relationships and everyday life.

Darren and Michael in particular strongly resisted moving out and felt they had been pushed into it against their will before they were ready, *'My social worker pushed me into it'* (Darren), *'When I was still at home and when everybody left I was still there and I didn't want to leave yet 'cause it was so... too much for me'* (Michael). They both felt that they had not been listened to and that their priorities had not been taken into account.

Perhaps as a result of the move out of the family home often being rushed and poorly planned, participants rarely stayed in the first place they moved to, with many experiencing further residential transitions, again often not by choice. Greg, Darren, Liam and Michael had all lived in several hostels and flats and Daniel had moved twice, the second time to move closer to his mother. Even when participants had moved to somewhere they liked, they often had to move on, for example Michael was moved out of the African Caribbean area of the city due to crime in the area. Only Jack had remained in the first place he had moved to; this suggests that advance planning is important in order for service users to find accommodation that meets their individual needs.

For some, an inability to control or have a say over events in their lives applied to more than just their experience of residential transition. For example Greg spoke about how he had no control over being able to see his son, *'Well, except for not seeing my son. She [son's mother] can't get someone... that's what she says...'*

- *Lack of informed choice*

Although some participants had been given a say in choosing where they lived, for many this choice seemed limited. For example, Liam talked of someone else picking the hostel he moved into and of not visiting it first. Although he said that he had chosen his new flat himself he then went on to say that he had only been shown one place, suggesting that the choice he had made was not particularly informed. Michael also spoke of choosing his final flat himself but that he had made this decision based only on its size and ultimately was dissatisfied with it being so far away from Caribbean shops.

- *Enforced loss*

For many, moving out of the family home represented a multitude of losses, not just of their family, but also of their belongings, community, friends, daily routine and even pets. Daniel was moved to a completely different city which made visits home difficult. Michael spoke at length about being *'gutted'* that he could not take his dog with him when he moved. Only Greg and Jack moved into places nearby to their family home allowing them a greater sense of continuity. These losses had left some participants desiring more routine and predictability and wanting to feel more settled.

Frustrated by dependency

Moving out of the family home often led to an increase in participants' dependency on others for support. For all participants but Jack, this resulted in a strong sense of frustration as often those they relied upon did not fulfil their roles and so left them unable to achieve their goals.

- *Feeling unsupported/neglected*

There were many instances when participants felt unsupported and neglected by professionals. Greg talked about the lack of support he received in resolving both interpersonal and practical problems, often being told by those around him to avoid trouble and stay out of the way. Darren also spoke of feeling that staff would not or did not want to help him, '*Cause you're crying out for help and they're not willing to help you*', or of staff making promises that they did not keep. Michael talked about his requests for help often being rejected. Both Darren and Michael spoke of their anger that staff were not doing their jobs properly, '*I was pissed off with it because I decided, well, if I had their job, I would know how to do it*' (Darren). Both Darren and Michael had been drawn into caring for other residents when staying at a hostel, another example of staff not fulfilling their duties.

- *Wanting to do more*

Since moving out of home, Liam, Daniel and Michael all talked about not being able to carry out activities that they wanted to pursue as in order to do so they needed support that was unavailable. Liam spoke of feeling bored and wanting to do more but not knowing how, and Daniel described having to compromise on activities because he lived in a residential home and things often had to be done in a group. Michael also spoke of wanting to do more and in particular wanting to go to Caribbean shops.

Striving for autonomy

Many participants aspired to be autonomous and saw the move out of the family home as a means of achieving this goal. Such autonomy represented different things to different people but often referred to concepts such as independence, control, paid employment and freedom.

- *Independence and control*

All participants with the exception of Daniel spoke about desiring independence and control. For all but Jack, this was not something they had initially wanted for themselves, but was something that appeared to have been imposed upon them by others including families, professionals or college. However, despite this they now all spoke of this as a current goal, and

many on reflection saw their move out of the family home as something that had enabled them to achieve some level of independence and control over their lives. Being independent had different meanings for different people. Greg talked about it as meaning having his own 'crib' and 'gear' and being able to do whatever he liked. Darren talked about being independent and free, making his own decisions and feeling settled. Liam described his flat as being symbolic of independence, '*Being independent... That's what it's all about. Me own house*'. Jack spoke of wanting to be a man and feeling more confident and both he and Michael talked about having their own homes, being independent and making decisions for themselves.

- *Paid employment*

For Greg, Darren, Jack and Michael having a paid job was also an important part of being autonomous. Both Jack and Michael had paid employment, whereas Darren and Greg had had it in the past and wanted it again. At the end of each interview when I offered the participants money for their time, they all expressed pleasure and appeared proud that I had considered their experiences worth paying to hear.

- *Freedom*

Daniel did not speak about desiring independence or a job, perhaps because he lived in a residential home and this was not something that was encouraged by others. He did however talk about desiring freedom, something that had actually decreased rather than increased since his move out of the family home in contrast to the other participants who all lived independently and talked about being able to do more. He talked about wanting to be able to go out more on his own. With the exception of Darren who made reference to being free and independent, freedom was not talked about by the other participants; perhaps because they felt they had a level of freedom, it was not something that they felt motivated to comment on.

Being empowered

At times, experiences of both support and employment had provided participants with a sense of empowerment and helped them to realise their goals and deal with their struggle.

- *Empowering support*

Although empowerment was not talked about as widely as powerlessness, most participants did talk about how they had been encouraged and supported by others to do things during their residential transitions. Jack in particular had had a largely positive experience of moving out of home, presumably because he had been in control of his move.

He spoke about how others had encouraged him and helped him to make his own decisions throughout. Darren, Liam and Daniel all talked about how they had appreciated rules and boundaries during their transitions, especially when living in hostels or residential homes. Knowing what they should and shouldn't do had given them a sense of containment and had made them feel cared for, perhaps in a similar way to how they felt or were treated in the family home. Darren and Michael however warned of the need for staff and professionals to get a good balance between doing too much for residents and doing too little. It seemed doing too much could be experienced as controlling and overpowering, *'She used to be too bossy. She used to do everything for me' (Darren)*, whereas doing too little could be scary and make individuals feel uncared for, *'Very scary 'cause you didn't know what... all that time you didn't know what to do' (Michael)*. Darren also spoke of how support offered should match the needs of the service user. Staff should assess a person's independence and then teach them whatever they are unable to do on their own.

Empowering support was also spoken of in terms of receiving help from trusted organisations and staff and of being in control of the support that was received. Darren, for example, spoke of how he felt he could trust the people that supported him now as they kept their word and made him feel cared for, *'they're great because they keep their promises what they want you to do. They keep their promises. They don't tell you that oh we're going to get you new furniture for next week and then they don't come. They make sure you've got enough money, you know'*. He also felt more in control of the support, being able to pick when he wanted someone to come and what he wanted them do with him, *'and if you don't need them on that day you just ring them and say I don't need you this week, can you come next week'*. This made him feel like the relationship was more equal and that he was more respected.

- *Empowering employment*

Paid employment could also represent a means of feeling empowered. Both Jack and Michael were paid to provide teaching and training about African Caribbean people with learning disabilities. This role seemed to give them a feeling of pride and status that the other participants did not have.

4.2 Superordinate Theme Two: Connectedness

Many participants described how their experiences had often made them feel unwanted and of how they were repeatedly trying to form connections to people and groups in order to feel accepted. Their experience of moving out of the family home had often triggered these feelings, but experiences elsewhere in their lives had also made them feel this way.

Feeling unwanted

Feeling unwanted either by those close to them or by the wider society was a dominant theme for all the participants.

- *Rejected by people close to them*

All participants except Jack described how their move out of the family home had made them feel rejected by those close to them. Darren, Liam, Michael and Daniel all spoke of feeling pushed out of the family home by their relatives, leaving them feeling like they were unwanted or had been a burden, e.g. *'I was put into care when I was eighteen'* (Michael), *'Well it was to give my Mum a break'* (Daniel). These participants also spoke of feeling unwanted by friends, girlfriends, and professionals and having experienced repeated rejection and abandonment.

- *Feeling different from society*

All participants but Liam also spoke of a more global sense of feeling unwanted, and of being made to feel different from society as a whole. This was spoken of in terms of their ethnicity, learning disability, and age, indicating a sense of feeling disadvantaged due to more than one characteristic. Residential transition was one of several contexts that exposed participants to this feeling of being different.

Participants were generally proud of their ethnicity and did not think of themselves as being inherently different. However, most were aware that they could be considered to be different by the White majority. Some participants had been discriminated against due to their ethnicity both before and after their move out of the family home, *'Yeah I don't see nowt wrong with it but people think it's wrong with us that we're that colour but that's beside the point. People call us opposite way from Caribbean. They call me all sorts of names but I have to ignore that. They go by the colour. It affects me that way. I just don't like the colour. I like the colour but they don't like the colour and I don't like what they are saying'* (Michael). Feeling different in terms of ethnicity seemed to be an issue for participants during times when they were part of a minority ethnic group among the people with whom they lived, e.g. Michael struggled being the only African Caribbean child at school, Daniel spoke of feeling different to the Caribbean people where he grew up, and Greg moved to a flat in which he witnessed and was subjected to racism by his neighbours.

Jack and Darren also spoke of their awareness that their learning disability made them different. Jack talked about how his job involved campaigning for people with learning disabilities indicating recognition that they were often disadvantaged in some way. Darren

spoke of his anger and frustration that people with learning disabilities are often not given the same amount of respect and support as the general population.

Darren and Daniel also described not fitting in with others in terms of their age compared to the people they lived with. Both had experienced living with people much older than them which they had found difficult as they had not felt they had enough in common with them. Daniel talked about his current residential home where he was the youngest resident and how he would ideally like to live with people much younger than him. To him, the age of his fellow residents was far more important than their ethnicity.

Seeking acceptance

All the participants spoke of wanting to fit in and be accepted in both personal relationships and by the wider community. Often this search for acceptance seemed to have been prompted by the feelings generated by their residential transitions.

- *Wanting close relationships*

All participants spoke of their search for close relationships, something that had appeared to have started since moving out of the family home. For some this seemed to be a way of making up for the losses in close relationships they had experienced when they moved out; however for others the move out of the family home had simply provided more opportunities for meeting new people and making new friends.

Darren, Daniel and Michael all spoke of their current search for love and acceptance from romantic partners. Michael had been successful in his search for love and was getting married, something which he considered a risk, but a risk worth taking. Greg, Liam and Jack spoke more of wanting close friendships; Greg had started making efforts to form more equal friendships with his relatives and neighbours, and Liam and Jack had both experienced increased opportunities to make friends since their move out of the family home. Perhaps for Liam and Jack, their families had acted as substitutes to friends, meaning that once they had moved out they were more motivated to look for relationships outside of the family. Jack spoke of having made both African Caribbean and White friends, making him feel accepted by the wider community.

- *Belonging to a community*

Of all the participants, Michael spoke the most about wanting to be part of the African Caribbean community, describing how he felt he was missing out on Caribbean food and events in his current location. However, Daniel also spoke fondly about the Caribbean events he used to go to, and how he had been unable to take part in these when he had been moved

to another city. It seems likely that needing to belong to the African Caribbean community was an important issue for these two participants as they had experienced times when they could not belong to it, making them aware of how much they appreciated it when they could. As the other participants all lived in an African Caribbean area it may not have been an issue they were as consciously aware of.

- *Roles and status*

Creating or taking on roles seemed to represent a way in which participants tried to connect with and be accepted by those around them and by society. Greg talked a lot about the roles he had tried to take on, all of which appeared to be ways in which he could feel needed and valued by those around him. He talked of looking after people, advising people and disciplining his child when necessary. He also spoke of his role as a homeowner and the pride he took in having a *crib* and having money, things which made others jealous, *'I used to live in a flat but people got jealous 'cause I was making more money than them'*. Michael and Jack talked about their roles in their jobs and how they felt valued and accepted by those they trained. Michael in particular talked about people wanting to be like him, giving him the sense that he was a role model.

4.3 Superordinate Theme Three: Appraisal with Emotion

Participants often spoke about their hopes and fears surrounding their past, present and future experiences. Many had felt ill equipped to leave home and had faced a series of difficult challenges since moving out of home. Despite this, many were hopeful about their futures, and had many aspirations and dreams.

Feeling ill equipped to leave home

For many, the move out of the family home was very anxiety provoking. All participants initially found it difficult to cope with the move out of the family home. Even Jack, who chose to move out, reported feeling worried and sad about the move and feeling nervous and upset about living on his own. Darren spoke of feeling scared and frustrated, and feeling let down and disappointed with those around him. Liam talked about finding living on his own being strange at first. Participants worried about feeling vulnerable and how they would cope on their own.

- *Feeling vulnerable*

Three participants spoke about feeling defenceless and vulnerable. These feelings appeared to emerge following the move, when they were no longer surrounded and protected

by their families. Jack described feeling vulnerable and fearful of living alone, and feeling anxious that others may be more likely to take advantage of him. Greg and Daren had both experienced others taking advantage of them; again it seemed that families had offered a protective influence which was lost after they moved out of home. Interestingly Daniel did not talk about feeling vulnerable; perhaps living in a residential home offered him a level of protection that the others did not get from living independently.

- *Limited conflict resolution*

Four of the participants spoke about their difficulties in knowing how to cope with challenging situations. This was most striking for Greg who described how he would move house whenever things became difficult such as when he had practical problems with his accommodation or when there was conflict with neighbours or friends. Greg did not seem to know how to handle such situations appropriately and so found it easier to leave than attempt to solve them. He also talked about responding to confrontation with aggression, something he had been trying to avoid more recently as he did not want to get into trouble.

Liam also spoke of finding it difficult to solve interpersonal problems and at times felt that removing himself from such situations was the best solution, such as at college when he did not get on with some of his classmates and he left. Michael spoke of withdrawing and avoiding people too; when he could not get on with his fellow residents in the hostel he said, '*just went upstairs and did my own thing until they found me somewhere to go*'. Darren learnt to cope by keeping things to himself as he did not trust those around him to keep his confidence or help him. All these methods of coping left the participants feeling lonely and isolated and added to the chaotic nature of their lives. This is in contrast to Jack who had learnt from his family to persevere with rather than run away from problems and did not report finding it difficult to resolve problems or feeling lonely.

Hope for the future

Despite the difficult experiences all of the participants had experienced throughout their residential transitions, most talked about feeling hopeful about the future. Michael spoke of '*a turnover*', involving the new life he had ahead of him with his partner. Darren and Greg spoke about making fresh starts in terms of wanting a more settled and peaceful life with less upheaval and trauma. Daniel dreamed of having a girlfriend and living with young people. Only Liam and Jack did not talk of their aspirations for the future, instead seeming content to live day by day in the moment, '*I haven't got any dreams. Anything that happens, happens. I haven't got any dreams*' (Jack). Perhaps this was because they had achieved many of their goals already and did not have any strong ideas about how they wanted their lives to change.

5. Chapter Summary

This chapter provided an overview of the individual and group analysis for the six participants in this study. The following chapter will provide a summary of these findings and then reflect on the superordinate themes in terms of the wider literature, clinical implications and further research. It will also provide a critique of the study as a whole.

CHAPTER FOUR: DISCUSSION

1. Chapter Overview

This chapter provides a summary of the research findings and places them in the context of the wider literature on transition, disability and ethnicity. It then discusses the possible clinical implications and suggests some recommendations for clinical practice. This is followed by a critical evaluation of the study including its strengths and limitations and ideas for further research. The chapter concludes with final observations and personal reflections.

2. Summary of Findings

The aim of this research was to explore the experiences of African Caribbean people with learning disabilities who had moved out of the family home. As described in the previous chapter, themes emerged that were applicable to the experience of residential transition but that also captured experiences in the rest of the participants' lives. Participants had unique individual themes but often these could be conceptualised as different dimensions or subthemes of the same superordinate theme. The group analysis produced three superordinate themes; struggle, connectedness and appraisal with emotion.

2.1 Struggle

Participants spoke of a struggle between wanting support that empowered them to achieve their goal of greater autonomy, and being frustrated by feelings of powerlessness and having to depend on others for support. Powerlessness dominated many participants' experiences of the residential transition but also appeared to relate to other areas of their lives. They described having limited control and choice over situations and of experiencing repeated enforced losses of family, friends, partners, homes and possessions. All participants spoke of desiring autonomy although this was not always a goal initiated by themselves. Autonomy represented different things to different people such as independence, control, paid employment and freedom. For many, moving out of the family home was symbolic of gaining independence. Participants spoke of the frustration at having to depend on others more during and after their residential transitions, especially when those they depended on often let them down. Feeling unsupported and neglected by carers was a common experience and some participants spoke of being frustrated at their lack of activities and wishing they could do more. Despite their difficulties with support, most participants had felt empowered at some point by the support they received and/or having paid employment. Such experiences had made them feel valued, respected and equal.

2.2 Connectedness

All participants spoke of wanting to be connected to other people and communities. Most had experienced the move out of the family home as a rejection or abandonment and this, coupled with other experiences of feeling unwanted, had made them feel isolated and alone. They also spoke of feeling different from other people in terms of their ethnicity and disability and of having been discriminated against. These experiences had left participants striving to be accepted, not only by those close to them but also by their community. Participants often sought out close relationships with friends or partners, and tried to achieve a sense of belonging and status through taking on valued roles in the community.

2.3 Appraisal with Emotion

All participants experienced some level of anxiety about leaving home regardless of whether or not the move had been planned. Living outside of the family home made participants feel vulnerable; without their families to protect them they were concerned that they could be taken advantage of by others. Many also talked about finding it difficult to solve problems and cope with challenges once they had moved out. Often participants avoided or escaped from problems as they did not know how else to resolve them. However, despite their anxieties during the residential transition(s) and the difficulties they had encountered, some participants spoke of their aspirations for the future and described a sense of hope about what was yet to come.

3. The Wider Literature

Although this study is unique in its aims, the findings can be discussed in relation to the wider literature on transition, disability and ethnicity. The small number of participants in this study inevitably means that generalisations should not be made; rather the following section seeks to comment on whether the findings in this study support, contradict, or add to the available literature.

3.1 The Transition of Leaving Home

Reasons for moving home – transition profiles

In their research exploring the most common reasons for transitions out of the family home, Essex, Seltzer & Krauss (1997) described three transition profiles – normative launching, a response to a stress process, and postponed launching. Five out of the six participants in this study appeared to have moved out of the family home in response to some kind of stress process, including family conflict, breakdown or bereavement. This gives some support to the

validity of this transition profile, and suggests that this could be the most frequent type of move for people with learning disabilities. This also fits with the results reported by Alborz (2003) who found that the majority of participants (78%) had moved in response to a stress process. Alborz argued that there were three types of stress process; forensic involvement, family problems, and service difficulties. For the five participants in this study who moved in response to stress, all reported moving due to family problems; one can only speculate regarding how services and supports addressed or failed to deal with these difficulties.

The remaining participant in this study (Jack) moved out of the family home of his own volition, when he was in his mid twenties. In terms of the transition profiles suggested by Essex et al, this move could be seen as a 'normative launch' as the time and motivation for his move out of the family home could be considered to be similar to those of his non-learning disabled peers. It is interesting that none of the participants in this study experienced moves that fully corresponded to the postponed profile suggested by this model. This absence of experience does not of course disprove the existence of this profile, but it does at least give weight to the suggestion that it is less common.

Planning of residential transition

As many of the moves in this study were in response to a stress process, few were planned in advance, resulting in placements in hostels or homes that could potentially be viewed as unsuitable or inappropriate in some ways (e.g. Daniel relocating to another city away from his family or Greg and Liam having to live in temporary hostels). This appears to support the finding reported in the literature of the reluctance of families to plan moves in advance resulting in sudden and unplanned moves in times of crisis (e.g. Prosser, 1997; Hubert, 2006). As carers themselves were not interviewed during this study, it is difficult to know what prevented families from planning moves in advance. Participants themselves discussed a reluctance to move out, but were not asked to comment on the extent to which plans had or had not been made by themselves or their carers, and did not talk directly about other factors such as mutually supportive relationships or distrust of services as described in some research (Gilbert, Lankshear & Peterson, 2008; Bowey & McGlaughlin, 2007). As a result the relevance of such factors can neither be supported nor refuted by this study.

The experience of Jack who planned his move in advance could be seen as a good example of how planning can lead to a more successful transition. As Jack had the time to explore his options and did not feel rushed or pushed into his move, he was able to find a flat that suited his needs and priorities without having to compromise on what he wanted. This

serves as a good example of the recommendation for forward planning discussed by the Department of Health's Independence, Wellbeing and Choice paper (2005).

3.2 Quality of Life Pre- and Post- Move

Despite the reluctance of many participants to leave the family home, the experiences they described pre- and post- move did not always suggest that living with the family was associated with a better quality of life.

Although living in the family home often provided more emotional and practical support, participants also described less autonomy, freedom, and opportunities for friendships. This was also reported by Seltzer & Krauss (2001) who spoke of service users receiving more support but using fewer services and having fewer friends when they lived with their families. Interestingly, in this study the exception to this finding lay with Daniel, who had been moved into a residential group home rather than into a supported living network. This had impacted negatively on his freedom and autonomy, which is reflected in the findings reported by the CEDR (2008) which described a lack of choice and control in the lives of learning disabled people living outside of the family home. This difference may be attributable to the type of housing that Daniel had been moved into, but this needs to be explored with further research before such a link can be confirmed.

In line with the American research conducted by Baker & Blacher (1993) and Seltzer Krauss, Hong & Orsmond (2001), the majority of the participants in this study maintained relationships with their families when they moved out of the family home. Although Daniel was moved to another city, his family continued to visit him and with the exception of Michael whose parents moved back to the Caribbean, all the other participants continued to see their families regularly. Darren even talked about how he now got on better with his mother as he had become less dependent on her. The findings reported by Bignall & Butt (2000) regarding African Caribbean service users' desire to remain close to their families when moving out was also supported by this study. All participants except Michael saw this as a priority, with difficulties reported when this was not achieved.

3.3 The Lives of People with Learning Disabilities

The participants in this study often described having limited control during their residential transitions and their everyday lives. Many had difficulties with the support they received, had restricted daily activities and struggled to form close relationships. Only two of the six participants had paid employment, whilst another participant carried out voluntary work. These characteristics have been reported as being common to all people with learning

disabilities regardless of their ethnicity as described in the Centre for Disability Research (Emerson & Hatton, 2008) and the White Paper, Valuing People Now (Department of Health, 2007). Thus these characteristics do not appear to be specific to people from minority ethnic communities.

The findings in this study also support the idea that due to the context of the family setting, people with learning disabilities are not always encouraged to develop the same level of 'personal assertiveness' as their non-disabled peers (Baker, 1991). Many participants described feeling protected at home, and few appeared to have had many opportunities to experiment, take risks and learn from mistakes (Shepperdson, 2000). This of course may have placed them at a greater risk of struggling when they had to move out of the family home.

3.4 The Lives of African Caribbean People

The strong sense of struggle that emerged from the findings in this study is particularly interesting given the longstanding historical context of African Caribbean people fighting against oppression. Throughout history, African Caribbean people have been subjugated within Western societies which practiced slavery and segregation due to a belief in White racial superiority (Fernando, 1998). African Caribbean people have been forced to struggle against this oppression and often chose to engage in forms of resistance rather than be passive victims (Fryer, 1984). None of the participants in this study came across as passive victims; instead they spoke of striving to deal with the challenges of life. It may be that this attitude or way of life has been shaped by such a cultural history; this would fit with the idea in the Expanded Family Lifecycle Model (Carter & McGoldrick, 2005) that individuals are embedded within and influenced by a wider socio-political context and history which can influence the way in which individuals and families approach challenges.

It is also interesting that the issue of control came up so frequently in all the participants' accounts. As described in Chapter One, African Caribbeans have often been portrayed in Western psychiatry as 'dangerous' and 'in need of control' (Fernando, 1998), perhaps because of their history of resistance. Participants often reported lacking control over their residential transitions and everyday lives and aspired to be independent and in control; this finding fits with the historical context of African Caribbean oppression.

Although participants spoke of feeling different from society in terms of their ethnicity, they also spoke of a sense of pride. Again, this is an issue that has historically been linked to Black or African Caribbean people, for example the 'Black Pride' movement in the US was related to the civil rights movement. Whether or not the issue of pride is of particular

significance to the participants in this study because of their ethnicity cannot of course be confirmed by this study, but future research could explore this further.

Although the idea of 'double discrimination' was not explicitly explored with participants in the interviews, many did discuss feeling different from society in terms of both their ethnicity and their disability. This gives some support to the idea that people with learning disabilities from minority ethnic communities are often marginalised for belonging to two different minority groups, resulting in a greater risk of discrimination (Baxter et al, 1990).

3.5 Impact of Transition on Psychological Wellbeing: Psychological Models of Transition

Model of Personal Change (Fisher & Savage, 1999)

Participants in this study reported a variety of feelings during the process of transition including happiness, excitement, fear, anxiety, disappointment, frustration, sadness and anger. The emotional states described by Fisher & Savage do encompass these emotions to some degree, and many of the emotions reported by participants are cited by this model. However, participants often described this as a fluid process whereby they moved backwards and forwards between emotions rather than through a set process of emotional stages as proposed by the model. In addition, some emotions such as guilt were not articulated at all. The absence of some emotions may be partly due to the difficulty some participants had in identifying and describing their feelings. When this occurred, emotion cards were used as prompts which may have shaped the participants' responses. Even so, of the six participants, not one described all the supposedly universal emotions central to this model. It also seemed that the emotions participants described and the extent to which they felt each emotion was somewhat dependent on the amount of control and choice they had in their residential transition. For example Jack, who chose to move out of the family home, described a much wider range of positive feelings such as happiness and excitement compared to other participants. The impact of control upon the experience of transition is briefly mentioned but not fully accounted for in Fisher & Savage's model. The findings of this study would suggest that perceived control and choice is a highly significant part of the transition process. This, together with the other limitations described, seems to suggest that their model is too simplistic to account for the individual variance present in the experience of transition.

Lifespan Model of Developmental Change (Hendry & Kloep, 2002)

The findings of this study appear to fit relatively well with the ideas proposed in the lifespan model of developmental change. On the whole, participants found the transition out of the family home very difficult, and this seems to make sense when considering the limited

amount of 'resources' they had available to them; their learning disability placed them all in a position of disadvantage and many reported poor social resources such as difficulties communicating, reduced opportunities for friendships, and experiences of being discriminated against by their peers due to their ethnicity. In addition to this, some lacked daily living skills such as cooking and bill paying, and for the majority positive feedback resulting in self efficacy (a concept akin to empowerment) was not a frequent occurrence. More structurally speaking, being African Caribbean placed them in a minority group with the associated challenges described previously in the literature review. Indeed, several participants described challenges specifically associated with their ethnic identity predominantly related to the experience of discrimination.

Having such a small repertoire of resources would have placed the participants in a vulnerable position. Whilst many were happy to continue living at home in a state which could be conceptualised as either 'unhappy or contented stagnation' according to Hendry & Kloep's model, the external decision for them to move out of home placed them at risk of lacking the necessary resources to tackle such a challenge. According to Hendry & Kloep, such an external change would have been even more difficult for participants as it would have represented a non-normative off-time shift, i.e. for most it occurred at a different time to their non-disabled peers (usually at a delayed time as found by May, 2000). Participants also spoke of their frustration since moving out of the family home at not being able to achieve the typical goals of others such as having paid employment or sustaining romantic relationships. These would represent the challenges associated with non-normative non-events in Hendry & Kloep's model.

The experience of Jack who was the only participant to plan his transition also fits well with this model. As his transition was not an external change, he was able to prepare for the transition, and develop his pool of resources until he felt ready to take on the challenge of moving out.

This model is helpful in the context of this study as it serves to place the experience of transition in an understandable and theoretically sound framework. However, for the participants in this study this model is limited in terms of its description of resources and the associated difficulties of gaining such resources, including having to depend on others, facing stigma and discrimination, being taken advantage of, and lacking autonomy, choice and control. It also fails to offer suggestions as to how individuals can regain or develop their resources thereby enabling a move from a state of decay to a state of stagnation or development. In this study, participants described trying to do this in several ways including belonging to a community, taking on valued roles, and gaining employment. The actions of

others also appeared to enable this, for example when participants were encouraged and supported by staff. All the above factors relate to the individual's relationship with other people, organisations and communities, suggesting that it may be more useful to view the individual's development as occurring within a wider systemic context.

The Expanded Family Lifecycle (Carter & McGoldrick, 2005)

The transition of leaving the family home characterises the first stage that is proposed in the expanded family lifecycle, that of 'leaving home: single young adults'. For Carter & McGoldrick, this stage involves the individual accepting emotional and financial responsibility for the self through various developmental tasks. In order for this stage to be successfully navigated, the individual needs to differentiate themselves from their family of origin, develop intimate peer relationships, and establish themselves in respect to work and financial independence.

These proposed developmental tasks do seem to resonate with some of the themes that emerged from the participants' accounts. Differentiation from the family of origin and gaining financial independence can both be seen in terms of the theme of striving for autonomy, which encapsulates the desire to become more independent, have more control and find employment. The development of intimate peer relationships also featured in the participants' themes, with many participants talking about wanting to be accepted by others and have romantic relationships. Struggling to achieve these goals was repeatedly described, with factors such as a lack of resources, dependency on others, and experiences of rejection and discrimination all acting as barriers to success.

Carter & McGoldrick's model also postulates that difficulties in navigating the above developmental tasks can lead to problems in future relationships and transitions. For the participants in this study, many of the developmental tasks were proving hard to achieve. Attempts for autonomy were often thwarted by the reality of their dependency on others, gaining paid employment had only been achieved by two participants, and only one participant seemed to have established a long term successful romantic relationship. If Carter & McGoldrick are correct in their hypotheses, these difficulties place all the participants at risk of further problems throughout life. Some of the participants did indeed talk about how their inability to achieve certain goals had impacted on their lives. For example, Darren talked of struggling to achieve autonomy because of being let down by those who were supposed to help him. This, together with his repeated experiences of loss and rejection, had led him to be very mistrustful of people and be cautious about talking about his feelings. This appeared to

have ultimately made it difficult for him to form healthy personal relationships and had often led him to feeling isolated despite his strong need and desire for love and care.

The idea that stressful life events at one level of the family system can affect other levels was also supported by the findings of this study. Thus, when parents were struggling with bereavement or conflict, it of course impacted on the participants themselves, not only emotionally but also in terms of their daily lives.

Transactional Model of Stress and Coping (Lazarus & Folkman, 1984)

For most participants in this study, the transition out of the family home happened outside of their control to some extent. According to Lazarus & Folkman, when individuals do not have control over stressful events, emotion focused coping strategies such as wishful thinking, avoidance or minimising can be particularly helpful. This is because engaging in practical problem solving would not result in relieving the stressor, and so instead it is preferable to try and cope with the emotions the stressor generates.

Participants in this study did discuss their lack of control and choice around the time of transition and some did talk about the way in which they coped with this. Some spoke of avoiding people, others spoke of refusing to trust others or open up, whilst others spoke of running away from situations and constantly trying to start afresh. The extent to which these strategies could be seen as being emotion-focused or problem-focused is highly dependent on the individual's particular context, experience and appraisal. It does seem however that many of the participants struggled to relieve the stress upon them, suggesting that their emotion focused problem solving was limited.

One of the things that became apparent through its absence of description was the lack of emotional support provided by professionals. When talking about the staff that supported their transitions, most participants spoke of them organising the move, taking them shopping, paying their bills and so on but none talked of receiving emotional guidance or care. This is surprising given the emotionally vulnerable position many described being in at the time, especially for those who were battling feelings of being unwanted and rejected. It is possible that the participants did not speak of seeking or receiving emotional support because they found it difficult to talk about – traditionally boys and men are not always encouraged to speak about their emotions and may feel too proud to do so. Whether or not being a Black man made this even more difficult for participants is not possible to establish.

4. Clinical Implications

The findings reported in this study have several implications for clinical practice and the way in which professionals can offer support and guidance to service users.

Professionals first and foremost can use the findings to develop their understanding and awareness of the experiences of service users and how this impacts upon their future goals. Whilst the experiences of the six participants in this study cannot be generalised to all African Caribbean people with learning disabilities, the themes that emerged from the analysis can be recognised and explored when working with such service users. In particular, consideration could be given to the sense of struggle that often appears to dominate such transitions and more general lives, the desire for autonomy and independence, the need to feel accepted and connected to others, and the way in which transitions can leave service users feeling emotionally vulnerable. This study also shows that it is important for staff to think about the extent to which their own roles empower or prevent service users from achieving *their* goals.

It is not possible from this research to know whether the themes that emerged from this study would be common to other ethnic groups or whether they are specific to African Caribbean men. Until further research is carried out with other ethnic groups, it is therefore difficult to know whether professionals should treat African Caribbean service users differently to others. However, in the absence of any parallel research among other ethnic groups regarding residential transition, it could be argued that the findings from this study may well be common to all people with learning disabilities. This proposal needs to be tested empirically with a wider range of ethnic groups but in the meantime, professionals should bear in mind the key findings to come out of this research as this should help them to interact with their service users in a more compassionate and empathic way.

The findings of this study show that some goals (e.g. that of independence) may have been at least initially imposed on service users by professionals or other organisations such as the education system. The imposition of such goals may well be the result of professionals feeling under pressure to implement national policies and guidelines which encourage universal goals of independence (e.g. the report produced by the Commission for Social Care and Inspection entitled 'Supporting people - promoting independence', 2006). Whilst independence was talked about by all service users as being a goal they now wished to achieve, it seemed that this may not have always been something they wanted. Professionals should ensure that their definition of concepts such as independence match that of the service user, as different people can ascribe different meanings to such concepts (e.g. carrying out household tasks vs. living independently vs. making decisions vs. having a job). Service users'

transitions appeared to be more successful in contexts in which they and the professionals involved in their care had agreed upon shared goals and their priorities had been heard. This is especially important given the more recent role of healthcare professionals and especially Clinical Psychologists of making decisions on behalf of service users when they are judged to lack capacity. Many of the participants in this study moved out of the family home before the most recent legislation and guidelines were published regarding capacity decisions (e.g. Mental Capacity Act Code of Practice, 2005; British Psychological Society, 2007); it is therefore possible that service users who have moved out more recently have benefited from this guidance as the professionals involved in their care should have had an increased awareness of how to make decisions in the best interests of their service users.

Several participants talked about examples of good practice in which the support they received was empowering and had helped them to move towards their goals. This kind of support underpins the following clinical recommendations to emerge from this study in relation to crisis prevention and the provision of appropriate support.

4.1 Crisis Prevention

- Due to the high proportion of moves that occur in response to stress, earlier and better monitoring of families should take place so that support can be offered when it is needed rather than only in times of crisis.
- In order to increase access to support for families from minority ethnic groups, more proactive intervention and support should be offered.
- Support should be offered in helping service users and families plan for moves in advance in order to avoid the inevitable difficulties associated with crisis moves. This may need to incorporate an educational component so families and service users can understand the risks associated with delayed planning.

4.2 Support Offered

- A thorough assessment of needs should be carried out so that individualised support can be offered in a constructive way, e.g. by teaching rather than doing everything for the participant or not doing anything at all. This idea is similar to the Vygotskian concept of the Zone of Proximal Development (Vygotsky, 1962) in which an adult or teacher structures interactions and instructions in small steps based on the tasks the learner is already capable of performing independently (also called scaffolding). The teacher should

gradually reduce the level of support until the learner can move through all the tasks independently.

- The cultural needs of service users should be identified so that residential transitions can ensure the continuity of access to culture specific places, activities and people that are important to the service user.
- Advice and encouragement that help the participant to problem solve tasks and do not reinforce the problems they already have should be provided, allowing for an increase in self esteem and self efficacy.
- Service users should be listened to, believed and have their priorities heard. This was a frequently talked about issue for service users. Some spoke of struggling to communicate with professionals and be understood; this may indicate a greater role for advocacy when planning transitions.
- Service users need to have control over the support they receive e.g. being able to choose when a support worker comes round and what kind of help is needed. In order to do this, professionals may need to become more proactive in providing information and options to service users so they know what services are available.
- When possible, professionals should keep any promises they have made to the service user. For service users, professionals keeping their promises was an important part of feeling respected and like an equal.
- There should be continuity of care with professionals i.e. service users should not be passed from one person to another without being told and without having the opportunity for planned endings. Service users can become attached to professionals and also are forced to depend on them greatly. They may have also experienced many losses and this needs to be taken into consideration when planning endings.
- Rules and boundaries should be put in place so that service users understand the limits to what they can and cannot do and what they should and should not expect from professionals. Having rules and boundaries appeared to give participants a sense of feeling cared for and thought about.
- Professionals should recognise that residential transitions can be emotionally vulnerable times for service users regardless of whether or not they have had an active role in planning. Therefore professionals need to offer emotional as well as practical support to service users throughout the transition period.
- The participants in this study described difficulties in coping with problems. In particular practical problems and interpersonal conflicts often seemed to result in avoidance,

running away, and moving house. This led to participants leading chaotic and isolated lives. Professionals therefore need to support service users in thinking through and trying out alternative coping strategies when faced with difficulties.

5. Limitations and Strengths of the Study

The following section summarises the limitations and strengths of this study and critically evaluates its quality according to established guidelines for qualitative research.

5.1 Limitations

This study has limitations in terms of both its sample and the scope of the interview schedule.

Sample

There are several shortcomings regarding the sample used. Although the recruitment process was open to participants of both genders, the final sample only consisted of male participants. This appeared to be the result of the recruiters only being able to identify male participants rather than potential female participants being overlooked. Only one female participant was identified and approached to take part in the study; however she was anxious about meeting new people and declined to attend a meeting to discuss participation. It is possible that the difficulties in recruiting females may represent a tendency for more male than female African Caribbean people with learning disabilities to move out of the family home. The ratio of male to female African Caribbean service users living outside of the family home has not been reported in the available literature and so it is difficult to know whether or not this is a widespread phenomenon.

The sample used in this study was relatively homogenous as is recommended by the methodology used. Participants were all African Caribbean, were all male, all had been diagnosed with a learning disability and had all moved out of the family home. However, five had moved into a supported living network and one had moved into a group residential home which may have created some variability in the data. In addition to this, although all participants identified themselves as African Caribbean, only one participant chose to use this as the term that most accurately described his ethnicity. The remaining participants used the terms Black British, Black African, Caribbean and mixed race and one participant (Daniel) actively distinguished himself from the Caribbean population. There is some evidence in the literature that African and Caribbean people view their ethnic identities in different ways (e.g. Lam & Smith, 2009). Whether or not these differences are strong enough to compromise the

validity of the African Caribbean ethnic grouping and thus impact on reported experience is difficult to assess.

There was also some variation between participants in the amount of time that had elapsed since the first move out of the family home, which had occurred between four and twelve years previously. This has implications not only for homogeneity of the sample but also in terms of the accuracy of participants' recall. However, research has shown that although people with learning disabilities can have memory difficulties as a result of their cognitive impairment, they have better autobiographical than semantic memory (Pennington & Bennetto, 1998; Kebbell & Hatton, 1999) and so are able to recall past events in some detail. Some participants did appear to struggle in their recall of the planning and process of the initial move when asked for details. However all were able to convey a strong sense of how they felt at the time and the main reasons and steps involved in moving out.

Scope of the interview schedule

On reflection there were certain issues that were not raised by the interview schedule which could have been included and which may have led to the generation of higher quality data. For example, it would have been useful to have further explored the coping strategies employed by participants, the type of emotional and practical support they received, and the impact of having a sibling move out of the family home before they did. It may also have been interesting to ask more specific questions about the impact of having a learning disability rather than only focusing on the experience of being African Caribbean.

5.2 Strengths

One of the main strengths of this study is the fact that it is the first piece of qualitative research to explore the experience of the transition out of the family home from the perspective of service users from a minority ethnic community. The small amount of research that has been done in this area has mainly focused on the reasons behind such transitions and the amount of planning that has been carried out and has largely been undertaken with White participants and carers rather than service users (e.g. Essex, Seltzer & Strauss, 1997; Alborz, 2003; Hubert, 2006). Only Bigby (1996) interviewed service users, and only Hubert explored the views of families from minority ethnic groups. This study is therefore the first of its kind to interview service users who come from a minority ethnic group about their experience of the actual process of transition.

A further strength of this study is that the findings can be used to inform clinical practice as described above. Although the aim of this study was to give a marginalised group of

people a voice and allow their experiences to be heard, the themes to emerge from the analysis have clinical utility and should not be viewed as a mere description of experience, but as a useful means of improving the quality of service provision for this group of people. The extent to which these findings are specific to this particular group (i.e. African Caribbean people with learning disabilities) is at present unclear due to the current lack of comparable literature, and therefore it is difficult to know whether clinicians should treat this group in a different way to other service users or whether the experiences of these service users are common to other ethnic groups and (dis)abilities. However, if further research is carried out in the future with service users from different groups, these findings can be used to ascertain the similarities and differences between them.

The interview process used in this study was specifically designed in order to enhance the communication of participants and help them to elaborate on their answers. The use of participatory aids including the three coloured cards, and the set of African Caribbean emotion cards suggested by the consultation panel acted as a means for the participants to communicate in a more concrete and accessible way with the researcher. In particular, the timeline which was created collaboratively towards the start of each interview acted as a useful means of helping the participants to develop a temporal sequence around their experience of transition, and acted as an anchor point for the duration of the interview. Having this concrete timeline to look at and reflect upon rather than having a more intense one to one conversation may have also helped the participants to feel less scrutinised and in the spotlight.

5.3 Critical Evaluation of Analysis: Quality Control

In order to assess the quality of this study as a whole, it may be useful to evaluate it according to the guidelines for qualitative research set out by Elliott, Fisher & Rennie (1999). They describe seven criteria which should be achieved in order for a qualitative study to be considered methodologically rigorous:

(i) **Owning one's perspective**

At the beginning of Chapter Two I set out my theoretical, methodological and personal orientations in order to convey my values, interests and assumptions and the experiences I myself have had in terms of disability and ethnicity.

(ii) **Situating the sample**

Due to confidentiality issues I chose not to describe each participant in depth in the form of pen portraits. However, I did provide details for each participant's gender, ethnicity, number of moves and current living circumstances under pseudonyms. Descriptions of the group in terms of their ages and time since the initial move were also provided. In addition to

this, the aim of the individual analysis was to give the reader a good sense of each participant's experience.

(iii) Grounding in examples

All of the themes described in the analysis have been supplemented with quotations from participants in order to ground the analysis in the data. The group analysis is a higher order analysis and as a result does this to a lesser extent. However, as many of the group themes are featured in the individual accounts in some way it is hoped that the reader feels they too have been adequately located in the data.

(iv) Providing credibility checks

Several strategies were put in place to ensure credibility checks occurred. Both research supervisors read at least one of the transcripts and analyses and provided suggestions and comments for reflection. They were also consulted at each stage of the analysis in order to gain feedback on the process as well as the findings. In addition to this, a peer researcher read one of the transcripts and offered some preliminary comments on emerging themes. These were then compared with those generated by the researcher, and where disagreement occurred (which was infrequent), discussions were held in order to ensure that the researcher's analysis was justifiable.

A member check, in which validation of the analysis is sought from the participants, was not carried out in this study. Although there are some merits to this strategy, IPA assumes that some of the interpretations made by the researcher will not be in the participants' awareness and therefore cannot be verified by the participants (Smith, Flowers & Larkin, 2009). There could be concern that in not carrying out a member check, common stereotypes and assumptions about this group of individuals could be reinforced. As a result extra care was taken in reporting the results in a respectful and compassionate way. A summary of the findings will be fed back to participants at a later date and any feedback gained from this will be given careful consideration before any work is published.

(v) Accomplishing general vs. specific tasks

The decision to present an analysis of individual themes alongside themes for the group as a whole was made in order to ensure that each participant's individual voice and account was heard. Although many of the individual themes were carried through to the group analysis, there was some variance between individuals which could have been overlooked if only a group analysis had been presented. It felt especially important to present individual themes considering the lack of opportunities many service users have in getting their voices heard.

(vi) Coherence

Both individual and group themes were collected together to form overall clusters. It is hoped that this made the presentation of the analysis more coherent and easier to follow.

(vii) Resonating with readers

It is hoped that the analysis has been presented in such a way that leaves readers feeling they can relate to the participants and their experiences.

6. Further Research

The findings presented in this study give clinicians and other professionals some understanding of the experiences of African Caribbean people with learning disabilities during the process of transition out of the family home. However, further research could extend these findings in the following ways:

- Exploring the experiences of female African Caribbean service users to see if they are comparable to the experiences of males
- Interviewing carers and staff groups to see how their experience of the service user moving out of the family home impact upon them and what resources they need in order to support the service user to the best of their abilities
- Carrying out longitudinal research which allows the experience of transition to be discussed as it happens, thus reducing the difficulties associated with retrospective accounts
- Using discourse analysis or other social constructionist approaches to explore the use of language in regards to issues such as power, control and difference
- Conducting research with other ethnic groups in order to compare and contrast the experiences reported by African Caribbean service users with the White majority and other ethnic minorities
- Investigating specific issues that may be important in the experience of transition, such as the impact of siblings leaving the family home first, and the styles of coping (emotional vs. practical) employed to cope with the difficulties associated with transition

7. Conclusions and Reflections

7.1 Conclusions

This study provides an insight into the way in which African Caribbean people with learning disabilities experience the move out of the family home. Although the number of participants who took part in this study was small, the method of analysis allowed the data to be explored in depth and resulted in the emergence of key individual and group themes. These themes all describe and interpret participants' experiences of moving out of home but some also go beyond the experience of residential transition and represent issues that feature in many other aspects of the participants' lives.

Although the findings cannot be generalised to the African Caribbean learning disability population as a whole, they should be considered by professionals when working with this group and can be used to inform clinical practice. The findings may well be common to all people with learning disabilities, but this cannot be confirmed until further research is carried out with other ethnic groups.

7.2 Personal Reflections

Carrying out this piece of research has been a rewarding and at times unpredictable process. Although I had anticipated that participants would have experienced difficult events such as loss and rejection during their move out of the family home, some of the events that participants described surprised me. I expected participants to place more emphasis on the way in which their ethnicity had impacted upon their lives and thought many may not have had their cultural needs accounted for when moving out of home. Although this was discussed by some of the participants, other themes emerged that I had not predicted. I was particularly struck by the way in which participants struggled to resolve conflicts and felt compelled to move on to other accommodation as a means of solving their problems. Hearing some of the more difficult experiences saddened me at times but I was also filled with a huge amount of respect and admiration for the challenges the participants had overcome throughout their experience of residential transition.

8. Chapter Summary

This chapter provided a summary of the findings of this study and then discussed them in relation to the wider literature on transition, disability and ethnicity. It then explored the ways in which the findings could be used to inform clinical practice. An overview of the strengths and limitations of the study was then provided followed by potential avenues for further research. The chapter ended with conclusions and personal reflections.

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APPENDICES

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| Appendix 1 | Initial Letter to Service User |
| Appendix 2 | Service User Information Sheet |
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| Appendix 6 | Letter of Ethical Approval from Research and Development |
| Appendix 7 | Transcriber Confidentiality Form |



Letter to service user

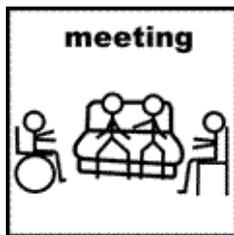
The experience of moving out of the family home



My name is Holly Jones and I am a Trainee Clinical Psychologist. I want to ask African Caribbean people with learning disabilities to talk to me about moving out of home.



Moving out of home should be as easy and supported as possible. I want to find out how this experience was for you and how workers can make it easier. I want your voice to be heard.



If you are interested in taking part and would like to find out more, we can meet up and talk about it.

You can bring someone with you if you want. You can change your mind at any time.



No, I am not interested.
Do not contact me.



Yes, I want to find out more.
Please contact me to arrange a meeting.

If **Yes**, please tell me the best way to contact you. I can call you or your keyworker to arrange a meeting

Name _____

Person to contact _____

Telephone number _____

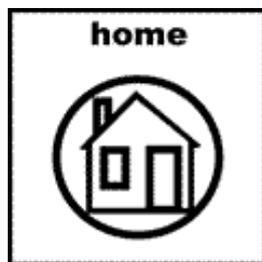


Information Sheet

The experience of moving out of the family home

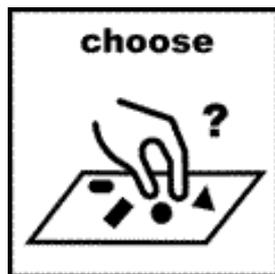


My name is Holly Jones. I am a trainee Clinical Psychologist. I am hoping to ask six African Caribbean people with learning disabilities to take part in the research. I will be asking you about your experience of moving out of the family home



Why is this study important?

Moving out of home should be as easy and supported as possible. I want to find out how this experience was for you and how workers can make it easier. I want your voice to be heard.



Do I have to take part?

It is up to you to decide. If you do want to take part, you will be asked to sign a form to say you agree. You can change your mind at any time.

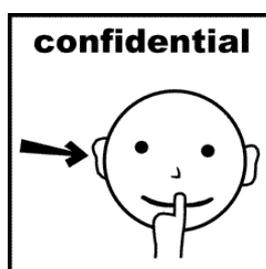


What do I have to do if I take part?

First we will make a timeline together. You can bring in pictures or objects to put on the timeline if you want. Then we will talk about your experiences before, during and after your move.



This might take one or two hours. You can choose whether to have one longer meeting or two shorter ones. I might talk to one of your family members too.

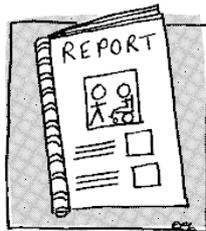


What will happen to the information?

What we talk about will be private. I will not tell anyone about it unless I hear about someone getting hurt. If this happens I may have to talk to your doctor or keyworker. I will tell you if I have to do this.



I will record what we talk about on tape and then write down what we said. Only my supervisor and I will know what we have talked about.



How will we tell people what we find?

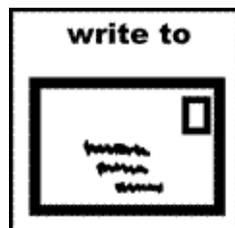
I will write up what we find in a report. The report will be sent to people who work with people with learning disabilities. There will also be an easy to read report. If you want, I will come and tell you what we find when the research is over

The report will have some of your words in it but the readers will not know who said what.



What if I have more questions?

If you would like to ask me any more questions, please contact me:



Holly Jones
Programme of Clinical Psychology
Charles Thackrah Building
101 Clarendon Road, Woodhouse
Leeds, LS2 9LJ



0113 2433719
umhij@leeds.ac.uk



What if I want to complain?

Please contact:

Dr Tom Isherwood

0113 343 0839

t.m.isherwood@leeds.ac.uk

Dr Ghazala Mir

0113 343 2732

g.mir@leeds.ac.uk



Consent Form: Service User
The experience of moving out of the family home



No, I do not agree to take part.



Yes, I do agree to take part

Name _____

Signature _____ Date _____

Consent taken by:

Name _____

Signature _____ Date _____

Appendix 4: Interview Schedule

1. Orientation

- Introduce self
- Check that the person can recall purpose of interview, refer to information sheet
- Check that the person is still happy to participate and has capacity to consent
- Repeat rules of confidentiality and that person can stop interview at any time (give visual prompt)

2. Context – general ‘easy’ questions to ease person into interview

- Can you tell me a bit about yourself?
 - o Prompt with more specific questions if necessary, e.g. How old are you?
Where do you live now? How long have you lived there for? What are your interests and hobbies? What do you do every day?
 - o How would you describe your ethnicity? What does being [ethnicity] mean to you?

3. Construction of a timeline - dates and places, use photos and pictures if available

Explain may be easier to map out big events in life including the move using a timeline and then we can talk about the move using the timeline as a prompt

4. Life in family home before residential transition

- What was life like when you were living at home?
 - o Who did you live with?
 - o What were your family relationships like?
 - o What did you do every day?
 - o What friendships did you have?
 - o How did you feel when you were living at home? (use feelings prompt cards?)
 - o How did being [ethnicity] affect life at home?

5. Reasons for moving/ planning for the move

- Can you tell me a bit about why you moved into X?
 - o Any changing circumstances?
 - o Whose decision was it?
 - o Did you have any worries about the move?

- How did you feel about moving out of home? (use feelings prompt cards?)
- Can you tell me about how the move was planned?
 - Sudden or gradual? How were you prepared for the move?
 - How much choice did you have in where you moved to and who you lived with?
 - How did you feel when all this was going on? (use feelings prompt cards?)
 - How did your family cope with the planning for the move?
 - How did the professionals support you in the planning?
 - Did you get to visit your new home and meet the other residents before you moved?
 - How did being [ethnicity] affect the planning of the move?

6. Life during the residential transition

- How were things just before the move?
 - How did you feel when the move got close?
- How was the move itself?
 - How did you feel during the move? (use feelings prompt cards?)
 - Can you remember anything about the day you moved?
 - How did being [ethnicity] affect the move?

7. Life after the residential transition

- Can you tell me about how things were in the few weeks after the move?
 - How was it different to living at home?
 - What kind of things were difficult?
 - What were the other residents like?
 - What were the staff like?
 - How did your everyday life change?
 - How did your relationships with your family change?
 - How did you feel? (use feelings prompt cards?)
 - How did being [ethnicity] affect life after the move?
- How have things changed since you first moved in?
 - Changes with other residents?
 - Changes with staff?
 - Changes with family?
 - Changes in feelings? (use feelings prompt cards?)

- Changes in everyday activities?
- Any difficulties?
- What are your feelings about the move?

8. Other

- Is there anything else you would like to talk about that I have not asked about?

9. Thanks

10. Debrief

- Ask how the person found the interview – how did they feel during the interview, how are they feeling now.

11. What happens next

- Explain what else will happen during the research
- Explain what happens with their information, check consent to using whole transcript and quotes
- Explain how findings will be fed back

Appendix 5: Letter of Ethical Approval from Leeds East Local Research Ethics Committee**Leeds (East) Research Ethics Committee**

Room 5.2, Clinical Sciences Building
 St James's University Hospital
 Beckett Street
 Leeds
 LS9 7TF

Telephone: 0113 2065652

Facsimile: 0113 2066772

14 October 2009

Miss Holly Jones
 2 Kelly Court
 The Square
 Horsforth
 Leeds
 LS18 5GU

Dear Miss Jones

Study Title: **A qualitative study exploring the experience of transition into residential services for people with learning disabilities and their family carers from African Caribbean communities.**

REC reference number: **09/H1306/69**

Protocol number: **2.2**

Thank you for your letter of 01 October 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

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 the 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).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|---|----------------|------------------|
| Covering Letter | | 19 June 2009 |
| REC application | | 19 June 2009 |
| Investigator CV | | |
| CV for Dr Ghazala Mir | | 10 June 2009 |
| CV for Dr Tom Isherwood | | 10 June 2009 |
| Interview Schedules for Family Carer | 2.2 | 19 June 2009 |
| Interview Schedules for Service Users | 2.2 | 19 June 2009 |
| Peer Review | | 10 November 2008 |
| Information Letter about the Trainee Clinical Psychology Research | | |
| Letter from Sponsor | | 18 June 2009 |
| Compensation Arrangements | | 02 October 2008 |
| Protocol | 2.2 | 19 June 2009 |
| Participant Information Sheet: Service Users | 3 | 01 October 2009 |
| Participant Information Sheet: Family Carers | 3 | 01 October 2009 |
| Participant Consent Form: Service Users | 3 | 01 October 2009 |
| Letter to John Hiley regarding R&D approval | | 01 October 2009 |
| Letter of Invitation to Family Carers | 3 | 01 October 2009 |
| Letter of Invitation to Service User | 3 | 01 October 2009 |
| Response to Request for Further Information | | 01 October 2009 |
| Participant Consent Form: Family Carer | 3 | 01 October 2009 |

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.

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| 09/H1306/69 |
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|---|
| Please quote this number on all correspondence |
|---|

Yours sincerely

Dr Carol Chu
Chair

Email: Amy.Beckitt@leedsth.nhs.uk

Enclosures: "After ethical review – guidance for researchers"
Copy to: Mrs Clare Skinner, University of Leeds

Mr John Hiley, West Yorkshire Mental Health Consortium

Appendix 6: Letter of Ethical Approval from Research and Development



Our Ref: 2009/158/L

West Yorkshire Mental Health R&D Consortium
 Research & Development Department
 North Wing, St Mary's House,
 St Mary's Road
 Leeds LS7 3JX

E-mail: john.hiley@leedspft.nhs.uk
 Direct Line: 0113 295 2387
 FAX: 0113 2952412

Dr Ghazala Mir
 Leeds Institute of Health Sciences
 Charles Thackrah Building
 101 Clarendon Road
 Leeds
 LS2 9LJ

30th August 2009

Dear Dr Mir,

RE: A qualitative study exploring the experience of transition into residential services for people with learning disabilities and their family carers from African Caribbean communities.

Following the recent review of the above project I am pleased to inform you that the above project complies with Research Governance standards, and has been approved by the relevant Consortium Trust management. We now have all the relevant documentation relating to the above project. As such your project may now begin within **Leeds Partnerships Foundation NHS Trust**.

This approval is granted subject to the following conditions:

You must comply with the terms of your ethical approval. Failure to do this will lead to permission to carry out this project being withdrawn. If you make any substantive changes to your protocol you must inform the relevant ethics committee and us immediately.

You must comply with the Consortium's policy on project monitoring and audit.

You must comply with the guidelines laid out in the Research Governance Framework for Health and Social Care¹(RGF). Failure to do this could lead to permission to carry out this research being withdrawn.

You must comply with any other relevant guidelines including the Data Protection Act, The Health and Safety Act and local Trust Policies and Guidelines.

¹ Details from:

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv

If you encounter any problems during your research you must inform your Sponsor and us immediately to seek appropriate advice or assistance.

Research projects will be added to any formal Department of Health research register.

Please note that suspected misconduct or fraud should be reported, in the first instance, to local Counter Fraud Specialists for your Trust. Consortium R&D staff are also mandated to do this in line with requirements of the RGF.

Adverse incidents relating to the research procedures and/or SUSARs (suspected unexpected serious adverse reactions) should be reported using **Trust incident reporting procedures in the first instance and to the chief investigator²**.

They should **also** be reported to:

The Consortium R&D Department

the Research Ethics Committee that gave approval for the study

other related regulatory bodies as appropriate.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Changes to the agreed protocol MUST be approved by both the Trust/s and Research ethics Committee granting initial approval, before any changes in protocol can be implemented. Copies of revised documents must be provided to the R&D Office. Advice on how to undertake this process can be obtained from R&D.

Projects sponsored by organisations other than the Consortium Trusts are reminded of those organisations obligations as defined in the Research Governance Framework, and the requirements to inform all organisations of any non-compliance with that framework or other relevant regulations discovered during the course of the research project.

Once you have finished your research you will be required to complete a Project Outcome form. This will be sent to you nearer the end date of your project (Please inform us if the expected end date of your project changes for any reason).

We will require a copy of your final report/peer reviewed papers or any other publications relating to this research. Finally we may also request that you provide us with written information relating to your work for dissemination to a variety of audiences including service users and carers, members of staff and members of the general public. You must provide this information on request.

If you have any queries during your research please contact us at any time. May I take this opportunity to wish you well with the project.

Yours sincerely

John Hiley

Research Governance & Programme Manager

² SUSARS – this must be within 24 hours of the discovery of the SUSAR incident

Appendix 7: Transcriber Confidentiality Form

Confidentiality Statement for Transcribers

Ethics Committee, School of Psychology, Leeds University

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

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

General

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

Transcription procedure

- 4) Transcription will be conducted in such a way that the confidentiality of the material is maintained.
- 5) I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access.
- 6) All materials relating to transcription will be returned to the researcher, and no copies will be made.

Signed.....Date.....

Print name.....

Researcher.....

Project title.....