AN INVESTIGATION INTO PATTERNS OF SPECIALIST SERVICE USE
AMONG AFRICAN/CARIBBEAN FAMILIES CARING FOR AN ADULT
WITH LEARNING DISABILITIES

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ABSTRACT

Twenty-nine parents from African/Caribbean backgrounds caring for an adult son or daughter with learning disabilities in the home setting were interviewed regarding family circumstance, service awareness and receipt alongside their experiences of and views about the services they used. In addition, carer stress levels and factors associated with stress were examined.

Carer awareness of both general and specialist services for people with learning disabilities were high however, service receipt was comparatively low. Carers were generally satisfied with the amount and quality of services they received. However, there was a general lack of confidence in the capability of services to help in times of crisis. Carers’ opinions about barriers to accessing services were explored alongside their views about how services could be improved.

A high level of stress was found in over half of the carers interviewed, which was associated with the number of health problems suffered by the carer and the level of support needs of the adult being cared for. Families were living in circumstances of material deprivation caring for an adult with a high level of need, generally with little support from services. The implications of these findings for services are discussed.
Chapter one

INTRODUCTION

Overview

Over recent years the nature of service provision for adults with learning disabilities has been widely researched, (e.g., Evans, Todd, Beyer, Felce, & Perry, 1994; Emerson & Hatton, 1996). However, very little systematic research has explored the support needs of minority ethnic groups (Baxter, Poonia, Ward, Nadirshaw, 1990; Nadirshaw, 1997). The few studies that have been conducted with people with learning disabilities from minority ethnic groups have been carried out mainly with samples from various Asian communities (e.g. Beliappa, 1991; Fatimilehin & Nadirshaw, 1994; Shah, 1995). Due to a paucity of research into the particular needs of African/Caribbean adults with learning disabilities and their families, little is known about patterns of service use and the experiences of this population.

Research into the uptake of mental health services among African/Caribbean communities has shown that they have poor uptake rates (e.g. Ahmad & Atkin, 1996; Fernando, 1991; 1995). Although service providers are aware that black and minority ethnic people with learning disabilities and their families have low service uptake rates (Begum 1995; Nadirshaw, 1997), relatively little systematic research has been carried out in this area. This study investigates the experience of, and service use among African/Caribbean families caring for someone with learning disabilities.

This chapter is divided into 4 main sections; the first section looks at the
disadvantaged status of people with learning disabilities and reviews the measures that have been implemented to attempt to reduce such disadvantage; the second section will examine the meaning of having a child with learning disabilities for different ethnic and cultural groups; the third will review the literature on service uptake and use among people from African/Caribbean communities; the final section will then outline the issues for investigation in the current study.

DISADVANTAGE AND DEVALUED GROUPS

According to the 1991 census, black and minority ethnic people make up 6 percent (approx. 3 million) of the total population of the UK, 1.6 per cent being black Caribbean, African and Black other. As the 1991 census missed about 1 million people, these figures are likely to be an underestimation of the actual number of ethnic minorities living in the UK. Moreover, many people from minority ethnic groups are now born in the UK and therefore British citizens; for example, 80 per cent of young African/Caribbean adults are British born and as such have a right to expect equal opportunities and treatment as their counterparts from the indigenous population (Soni-Raleigh, 1995).

However, recent research has shown that, along with other minority ethnic groups in Britain, African/Caribbean people face substantial inequalities, discrimination and disadvantage in almost every aspect of their lives (Ahmad & Atkin, 1996). They are for example, more likely than their white counterparts to: live in substandard housing in decaying inner city areas (Brown 1984); be employed in semi-skilled or unskilled jobs or be unemployed (Brown 1984); disproportionately under-utilise the available
social resources. In addition, they experience discrimination in education (DES 1985) as well as in health and social services (Ahmad et al, 1996; McNought, 1984; Pearson, 1985). Finally, black and minority ethnic people consistently receive less that their actual entitlement to services and benefits (Graig & Rai, 1996).

People with learning disabilities belong to a devalued group in society; historically, they have been feared and discriminated against. Until recently, people with learning disabilities have been ‘shut away’ in large institutions, which segregated them in order to protect society from their presence. This practice was due to some extent, to a lack of understanding about the nature of learning disabilities, as well as misconceptions and fears about, and prejudice against people with learning disabilities (McConkey & McGinley, 1988).

Little is known about the nature and prevalence of learning disabilities among African/Caribbean communities in Britain (Atkin & Rollings, 1996). However, it is clear that black and minority ethnic people with learning disabilities are doubly disadvantaged by virtue of belonging to two devalued social groups; in the UK, African/Caribbean people experience racism and people with learning disabilities experience stigma. Therefore, African/Caribbean people with learning disabilities are likely to experience double discrimination in a variety of settings, on the grounds of their disability and their race. This discrimination could be a major obstacle to African/Caribbean people with learning disabilities leading the lifestyle they would desire (Baxter et al, 1990; Nadirshaw 1997).
Impact of initiatives to reduce such disadvantage

Normalisation

Over the past 30-40 years there has been a shift in thinking about people with learning disabilities, their capabilities and how they should be treated. This shift has been informed by, for example, Wolfenberger’s (1972; 1980) work on normalisation. Normalisation underlies the planning of most services for people with learning disabilities, and advocates that this population should, as far as possible, be enabled to engage in the same activities and have the same human and legal rights as anyone else in society. In order to ensure this, the normalisation principles have been enshrined in legislation and government policy such as the Community Care Act (1990). The aforementioned improvements to the status of people with learning disabilities, should be brought about or implemented through approaches and resources that are not only valued by society as a whole, but also tailored to the needs of the individual with learning disabilities (Baxter et al, 1990), thus reducing the need for special or segregated services. It would also encourage society in general to view people with learning disabilities in a positive way and as a valued part of the community. Therefore, normalisation was intended to have a great effect on the way services for people with learning disabilities are organised, delivered and managed.

However, the normalisation philosophy encompasses and reflects entrenched social values and beliefs. It also makes broad assumptions about what is “valued” or “normal” in society (Nadirshaw, 1999) and encourages people with learning disabilities to aspire to and adopt the expectations, attitudes, behaviours and culture
of the dominant society. Moreover, despite Britain being a multi-racial and multi-cultural society, the power and decision making about polices and practice within services are generally the responsibility and the privilege of the indigenous population. Therefore, what is generally considered “normal” or “valued” are the needs, wants and wishes of the white majority (Baxter et al, 1990). Thus, the needs of black and minority ethnic people, which may be different and not ‘fit’ into the standard service provision, are at risk of being devalued and/or ignored.

Black and minority ethnic people with learning disabilities are expected to aspire to and adopt a value set including, diet, styles of dress, and even lifestyles, which may be in conflict with their own. In this manner, black and minority ethnic service users are by implication encouraged and expected to ‘fit’ into the dominant norms and value system and to relinquish their “differentness” (Nadirshaw 1999). This can have a damaging effect on black and minority ethnic people with learning disabilities and their families, leading to this client group being further devalued and disadvantaged. Ferns (1992) argues that, as services function within an inherently racist society, the principles of normalisation must take into account the reality of the covert racism present within white societies, and that this racism will be evident in the value system and norms of these societies.

Community care

The interest in community care has been increasing since the early 1970’s. The government White Paper ‘Between Services for the Mentally Handicapped’ (DHSS, 1971) recommended a change in the way care for learning disabled people was
delivered. It heralded the start of community care and residential facilities, and a move away from large institutions and hospital based care. The 1989 White Paper ‘Caring for People’ highlighted the manner in which community care was to be delivered. The 1990 NHS and Community Care Act specified that Local Authorities had the lead responsibility for developing services that offered an alternative to hospital care, on the basis of individual needs assessment (Nadirshaw, 1999). Over the past ten years there has been an increasing awareness of the importance of race and ethnicity for health and social policy. Specific statements have been made in several government white papers (e.g. Caring for People, 1989) regarding this issue. The 1989 White Paper ‘Caring for People’ stressed that:

“People from different cultural backgrounds may have particular needs and problems... minority communities may have different concepts of community care and it is important that service providers are sensitive to these variations... good community care will take account of the circumstances of minority communities and will be planned in consultation with them”. (DHSS, 1989, p10)

Whilst this statement recognises the importance of culture, ethnicity and race, government legislation has had a negligible impact on the lives of black and minority ethnic people. In practice, the needs of African/Caribbean people, along with other minority ethnic groups, have been unacknowledged, ignored or assumed to be the same as those of the indigenous population. In other words, actual practice in many areas and services remain ‘colour blind’. The ‘colour blind’ approach assumes a similarity of needs across different ethnic groups, and therefore that all service users
should receive similar services irrespective of their race, colour, class, ethnicity or religious backgrounds (Atkin & Rollings, 1996). When the needs of black and minority ethnic people with learning disabilities have been acknowledged, these have generally been designated as special and in need of specialist services. These specialist services tend to be segregated and usually marginalised from mainstream services and therefore mainstream discussion, policymaking and funding (Nadirshaw, 1999).

The Community Care Act (1990) aspired to meet the needs and uphold the rights of individuals who required support to live in the community. As mentioned above, it stressed the importance of needs assessments at both the population and individual level, and it emphasised that carers' needs should be assessed in their own right. It was assumed that by providing these assessments, the services 'bought in' by the health authority, would be more appropriate and improve the quality of people's lives. However, it has been argued that the unresponsiveness of the community care legislation to meet the needs of black and minority ethnic communities, has led to an increasing dissatisfaction with the helping professions and a further deterioration in the confidence of carers (Nadirshaw 1997; 1999). It has been argued that the disadvantage experienced by black and minority ethnic people with learning disabilities whilst using healthcare services, is a result of culturally inappropriate forms of care and service provision, in addition to being discriminated against (Nadirshaw 1999).

Services often ignore the needs of black and minority ethnic groups. Ahmad et al (1996) argue, although services claim to be “open to all”, that this policy can ignore
the fact that poverty and racial inequality disadvantage minority ethnic people and can create additional barriers to service uptake. These authors point out that, because services are organised according to the norms of the indigenous population, the linguistic and care needs of minority ethnic communities can be overlooked or ignored. For example, services may not provide help to those who do not speak English or food such as halal meat in day care services, which in turn may discourage some people from minority ethnic groups from using these services. In addition, because mainly white norms are enshrined in policies and procedures of services, low standards in service delivery and care may not be uncovered; this can result in the maintenance of prejudiced and racist beliefs and attitudes towards black and minority ethnic people with learning disabilities (Nadirshaw 1999).

There is also a lack of information, particularly translated into different languages, about what services are available, what they provide, and how to access them. This can result in the care management process being inaccessible to large proportions of minority ethnic communities. The assessment and care management process is rather complicated. Black and minority ethnic communities may be disadvantaged in this process by the lack of black advocates or independent care managers, who can provide them with independent support. In addition, care managers may not fully understand the diverse and varied needs of black and minority ethnic people and assume them to be the same as those of the indigenous population (Nadirshaw, 1999), which may complicate the evaluation of the care packages provided for this population.
Service providers often assume that black and minority ethnic groups, especially Asians, live in self-supporting extended families. However, even when this would be the preferred source of support, socio-economic or demographic factors may impact on the ability and willingness of families to provide this sort of care (Ahmad et al, 1996). Feelings of obligation may be strong, but the family may find it difficult to meet these obligations. Although the structure of Asian families has been changing from large extended families to smaller units, and large extended families have always been uncommon amongst African/Caribbean families in Britain (Barker, 1984), these communities are still perceived to “look after their own”. In fact, over a third of black African/Caribbean females seem to be living on their own (Bhalla & Blakemore, 1981); also there is a higher prevalence of lone parent families among African/Caribbean communities than in the indigenous population, leaving the burden of care for someone with disabilities on one person (Farrah, 1986).

In summary, the very principles and ideas put forward to improve the experiences and circumstances of people with learning disabilities in general, can have a detrimental effect on black and minority ethnic people within this group, and serve to further deny their needs and rights. A lack of understanding of the circumstances, experiences, and needs of black and minority ethnic people with learning disabilities could result in these policies perpetuating their disadvantage.

SHAME, CULTURAL MEANING AND LEARNING DISABILITIES

This section will discuss how the meaning of having a child with learning disabilities may vary across different ethnic and cultural groups (e.g., Black, Asian and Jewish), and explore how this cultural meaning can be influenced by religious beliefs. These
beliefs can represent a source of comfort and a means of facilitating coping. However, they can also have a negative impact, for example, resulting in people with learning disabilities and their families feeling stigmatised and shamed by members of their own ethnic, cultural and religious communities. Gilbert’s (1997) definition of shame as related to loss of social attractiveness and social status will be employed here.

This section will first of all discuss the small body of research relating to shame, learning disabilities and black communities. The remainder of the section will focus on the cultural meaning of having a child with learning disabilities, interfacing this with religious beliefs.

Shame

Shame is regarded as one of the most powerful, painful and potentially destructive experiences known to humans (Gilbert, 1997; Nathanson, 1994). Gilbert (1997) argues that all individuals are predisposed to experiencing shame. Shame is related to an innate human need to be viewed as attractive (attractive here is related to social desirability). Attractiveness in a variety of domains leads to the perception of social standing and social status. Thus, shame can be defined as the subjective experience of loss of attractiveness and social standing, for example, being devalued and diminished in the eyes of others.

Gilbert (1997) proposed that to gain status and acceptance within a group, an individual has to exhibit qualities that others will find attractive. Status is lost if there
is a failure to display these qualities, which leads to feelings of being devalued, resulting in feelings of shame. Gilbert (1997) suggests that humans are motivated to gain status, be accepted by others and create positive images of themselves in the minds of others. Shame is related to unsuccessful efforts to control the image an individual or group creates in others. People from black and minority ethnic groups are part of a socially stigmatised and devalued group, as are people with learning disabilities. Therefore, it is difficult for them to create positive images of themselves in the eyes of their communities and society in general. It is possible that individuals are more affected by being, and feeling stigmatised by their own communities, which in turn can lead to greater feelings of shame when social status is lost in these communities (Koegel, & Edgerton, 1982; Shah, 1998).

Shame, learning disabilities and black communities

Keman and walker (1981) in a study exploring the service use of African-American people with learning disabilities reported that they would often disappear into the community and avoid using learning disabilities services after leaving school, thereby ‘shedding’ the stigmatised label. This and other studies (e.g., Mercer, 1975) suggested that individuals with learning disabilities could lose the stigma and potential shame related to being labelled as ‘learning disabled’ when they left school. This was because they were no longer in schools or classes for people with disabilities, and were not as easily identifiable in the community.

Other studies of black people with mild learning disabilities (e.g., Koegel & Edgerton, 1982), argued that black people with learning disabilities did not disappear
into their communities after school and thus, did not ‘shed’ the ‘learning disabled’ label. Koegel et al (1982) reported on examples of black people who were reluctant to describe themselves as having learning disabilities and tried to behave in a similar manner to their non-disabled counterparts. Koegel et al (1982) suggested that rather than a loss of stigma, it could be felt more acutely when individuals were ‘discovered’ by their own community to have a disability. Experiences of shame resulted from feeling devalued and losing status in the eyes of their non-disabled peers, which in turn brought about a loss of confidence and had a negative impact on the self-esteem of the person with learning disabilities.

There is a body of research suggesting that religion and participation in church can supply black people with learning disabilities with support and enhance self-confidence; for example by teaching people how to speak in public (e.g., Baxter, 1990; Baxter et al, 1990; Rogers-Dulan 1998). However, there is also a small body of literature indicating that black people with learning disabilities can sometimes feel stigmatised by their religious communities (King, 1998; Koegel et al, 1982). King (1998) found that black people with learning disabilities sometimes felt pitied by their church peers and believed they were on occasion, discriminated against because of their disability. Koegel et al (1982) found that some people felt too embarrassed to take part in church activities and felt ashamed of their lack of ability, particularly in literacy skills and speaking up in church.

Cultural and religious beliefs affecting the meaning of learning disabilities

Recently there has been an increase in literature and research that has explored the cultural meaning of having a learning disabled member within minority ethnic
families. Although a small body of research has focused on black and Jewish people (e.g., Rogers-Dulan 1998; Rogers-Dulan & Blacher, 1995; Stahl, 1991), most of the research in this area has focussed on various Asian communities (e.g., Channabasavanna, Bhatti, & Prabhu 1985; Fatimilehin et al, 1994; Henly, 1983; Miles, 1992; Shah, 1995; Webb-Johnson, 1991).

Lack of understanding and misconceptions about learning disabilities

The literature suggests that black and minority ethnic families may have beliefs and attitudes about learning disabilities that differ from those of white families (e.g., Fatimilehin et al, 1994). This can be related to their lack of, or difference in understanding of the nature of learning disabilities and its aetiology. Some families appear to have misconceptions about the nature of learning disabilities or believe that learning disabilities can be cured by medical or spiritual intervention. This lack of or difference in understanding can affect service use (Miles, 1992). It has also been documented that some Asian families appear to believe that learning disabilities can be alleviated by marriage (e.g., Channabasavanna et al, 1985; Miles, 1992).

In his study of Jewish families, Stahl (1991) found that many of the Jewish mothers who were interviewed, believed in religious or magical causes for the learning disabilities of their offspring; for example fate, which some parents believed could cause an ‘evil spirit’ to enter the body and result in learning disabilities. Some researchers have reported that beliefs about learning disabilities being caused by the ‘evil eye’ and ‘bad spirits’ operate in different cultures, for example, within some Asian cultures (e.g., Fatimilehin et al, 1994; Miles, 1992). It is possible that these
beliefs could have an influence on parents' awareness of services, in conjunction with a reluctance to use formal services. This may be because they are not aware of the benefits that might be gained by service use, or may prefer to seek alternative forms of intervention.

A lack of understanding or misconceptions about the nature of learning disabilities can influence the type of intervention sought by carers. If families believe in the possibility of spiritual causes for learning disabilities, they may make pilgrimages to holy places. They may also seek the counsel and intervention of a spiritual leader in an attempt to find a cure for the disability. In a study exploring concepts of learning disabilities in Pakistan, Miles (1992) reported that it was common for families (particularly those from rural areas) to take their learning disabled relatives to saints' shines, because they believed that the rituals performed there could alleviate the disability. Stahl (1991) reported that Jewish families might petition their Rabbi to write a magic formula or passage from the bible, which was then dissolved in water and given to the learning disabled child to drink. It was believed that these measures could cure the disabilities. Parents might also purchase amulets from the Rabbi for the child to wear at all times, in the belief that this might alleviate or even cure the learning disability.

Religious beliefs that might influence the meaning of having a learning disabled offspring.

Within Hinduism there is a belief that when any living thing dies the soul or immortal spirit transmigrates from one body to the next (reincarnation). In what
condition the soul is to return is determined by one's actions in previous lives (Shah, 1995). Good works in previous life leads to rewards in the current life, but 'bad' works lead to punishment, this is called Karma.

It has been argued that a belief in Karma may help to provide an understanding and an explanation for having a learning disabled child. This can lead to a sense of resignation about or acceptance of having a child with learning disabilities, which in turn can facilitate adaptation (Webb-Johnson, 1991). However, Karma can also have a negative influence; 'bad karma' can be translated into the perception that having a child with learning disabilities means that, either the child or a member of the family had been particularly sinful in a past life (Hughes, 1984; Shah, 1998). If these views are widespread in Hindu communities, it is not difficult to perceive how families with learning disabled children could become stigmatised, therefore engendering feelings of shame. This shame can be borne by the entire family who may be seen as potentially more sinful than others (Shah, 1998). It is possible that the aforementioned beliefs if strongly held by families could result in feelings of burden and responsibility, which might lead to stress.

For Muslims, the Quran teaches that individuals should be sensitive and concerned about people with disabilities and not be patronising towards them or discriminate against them (Shah, 1995). It is taught that God has mercy upon the weakest in society and gives them rewards in such a way that will benefit others too. Many Muslims believe that if a disabled person (e.g., blind person) is living in the household, then blessings will be bestowed on others in that household (Shah, 1995).
Although the Quran teaches equality and acceptance, the reality is, that Muslims with a child with learning disabilities can sometimes feel isolated, devalued and stigmatised by their community for having a child with learning disabilities. There can be a sense of shame in having a ‘defective’ child in the eyes of the community (Shah, 1998). Parents might try to hide the person with learning disabilities rather than using formal services for people with learning disabilities making it obvious that they have a disabled child. This is because there is often a stigma attached to having a learning disabled member of the family, which in turn can have a negative impact on the marriage prospects of other members of the family (Hughes, 1984). The stigma and the possible consequences that can result from being identified as having a learning disabled family member, could possibly be related to some families apparent reluctance to use formal services. It is possible that the stigma attached to having a child with learning disabilities and the restrictions this might cause, could also lead to increased levels of stress in Asian families.

Judaism and Protestantism are bible-based religions in which there is a belief of ‘inherited sin’. The Old Testament teaches that the sins of the fathers are visited upon the children, up to the third and fourth generations (Stahl, 1991). As many black religious people are Protestant this belief can apply to them. If this religious teaching is taken literally, it could have an impact on the meaning given to having a child with learning disabilities for some Protestants and Jews.

Stahl (1991) reported that there was a strong tendency to apportion blame for having a child with learning disabilities in the Jewish community he studied. The belief in inherited sin meant mothers were often blamed for the learning disabilities of their
child. This could result in great shame felt by the mothers of a child with disabilities due to the possible presence of a belief that they were being punished for their sins.

In Protestantism the belief of inherited sin is not viewed explicitly as the fault of the mother. However, because mothers in the black community (as within most communities) tend to be the primary carers, they might take most of the responsibility and blame for producing a child with learning disabilities. This can result in the belief that they are being punished for past sins. There have been studies which suggest that some black mothers might believe that they are being punished, however, this does not appear to be a wide-spread belief or one that tends to endure (Flynt & Wood, 1989; Rogers-Dulan & Blacher, 1995, Rogers-Dulan, 1998).

Some cultures have viewed people with learning disabilities as "a gift from God" or in some way "divine". Rogers-Dulan (1998) reported that some black mothers believed that God had chosen them for the special task of caring for a child with disabilities. Others believed that their children were a blessing and showed that God had chosen them for this special purpose. These beliefs have been documented in previous research with black families caring for a learning disabled member (e.g., Rogers-Dulan et al, 1995).

For many cultures there is literature that suggests that comfort and support can be found in religion, which in turn helps families cope with the difficulties of caring for a learning disabled member. This has been reported by many researchers studying various Asian Communities (Elliahi and Hatfield, 1992; Fatimilehin et al, 1994; Shah, 1995; 1998). Religion and church communities have been shown to be a major
source of comfort and support within black communities (Baxter, 1990; Baxter et al, 1990; Flynt and Wood, 1989; Marion, 1980; Rogers-Dulan, 1998; Rogers-Dulan et al, 1995).

Flynt and Wood (1989) reported that black (African-American) mothers reported feeling less overwhelmed by having a child with learning disabilities than did white mothers. Marion (1980) reported that black mothers perceived and reported less personal burden in caring for their offspring with learning disabilities than did their white counterparts. The two studies mentioned above, reported that lower levels of maternal stress in black mothers were attributed to religion and family networks.

Recent studies indicate that for black carers, religion functions mainly in positive ways and facilitates adjustment to having a child with learning disabilities (Rogers-Dulan, 1998; Rogers et al, 1995). It has been reported that religion gives assistance in facing the challenge of the struggles involved in caring for a disabled offspring, and was used as a source of hope and comfort, and gave meaning to having a child with learning disabilities in black communities (Rogers-Dulan, 1998; Rogers et al, 1995).

Some of the beliefs that are mentioned in this section might not be exclusive to ethnic minority groups and cultures. It is likely that white British families caring for a person with learning disabilities will also have some of these religious beliefs (Mary, 1986; Stubblefield, 1977). However, religion does not appear to be of great significance to the majority of white British people (Baxter et al, 1990). In contrast, religion appears to play an integral role in the cultural beliefs and activities of the
groups that have been examined (Black, Asian and Jewish).

SERVICE PROVISION AND MINORITY ETHNIC GROUPS

Mental health services

A body of research suggests that black and minority ethnic communities have a low uptake rate of mental health services, due to a belief that these services are often inappropriate and do not meet their needs (e.g. Fatimilehin & Coleman 1998; Fernando, 1991; Soni Raleigh, 1995; Watters, 1996). This section will illustrate the above with reference to people from black and minority communities, with specific focus on African/Caribbeans’ experience with services for people with enduring mental health problems (psychiatric services), and community mental health services.

The obligation to address the diversity of needs in a multi-cultural society so that all members of the community have access to and receive an equitable service is widely recognised. However, most of the research carried out over the last 20 years attests to the fact that people from black and minority ethnic communities do not receive the mental health services they require (Fernando, 1991). A report by the Policy States Institute noted widespread racial discrimination in many British institutions, including the National Health Service (Brown, 1984).

There is also evidence for discrepancies in the way people from black and ethnic minority backgrounds and those from the indigenous population are treated. For
example, black people, particularly those from African/Caribbean backgrounds, are more likely than their white counterparts to be admitted to psychiatric hospitals and compulsorily detained (McGovern & Cope, 1987). Littlewood & Cross (1980) found that while in hospital, stereotyped attitudes and assumptions about black people lead to black inpatients being more likely to receive ECT and medication as opposed to psychotherapy; possibly due to staff believing the former two types of treatment to be more efficacious with black patients than the latter.

There is evidence for a low rate of service uptake by black and ethnic minority people with mental illness (Ahmad & Webb-Johnson, 1995; Fernando, 1991; 1995; Soni Raleigh, 1995). Research also suggests, that these communities are less likely than their white counterparts to make voluntary contact with mental health services (Soni Raleigh, 1995). Many people from African/Caribbean communities are aware of the fate of many black people who come into contact with the mental health system, and believe that the services they receive are inadequate and often inappropriate. Given the above data, it is not surprising that black people are mistrustful and reluctant to present themselves for treatment to a service which they believe commonly discriminates against different groups in Britain (Fernando, 1995).

Research examining the experiences of African/Caribbean people in their use of community mental health services, indicates that services may have difficulty making themselves accessible to black people, who in turn are reluctant to use them, resulting in a low uptake rate of these services (Atkin et al, 1996). Fatimilehin et al (1998) found that black families tended to be unaware of the available services, or were reluctant to use them, because they did not feel existing services could
appropriately meet their needs. Fatimilehin et al (1998) reported that black families were disinclined to use available services due to these being inappropriate to their needs and inaccessible, but also to their wish to avoid the stigma associated with using such services. Families did not seem to trust mental health services and felt involvement with services would result in an inability to control what happened to them. Fatimilehin et al (1998) suggested that the distrust on the part of the African/Caribbean community and the inappropriate response from the health services, are major forces accounting for the poor uptake rates of services observed within African/Caribbean communities.

The above section illustrated the experience of people from black and minority ethnic communities in their contact with mental health services. In order to discover whether people with learning disabilities have similar experiences of services, the next section will look briefly at research into service use by people with disabilities generally, before proceeding to examine service use of families from minority ethnic communities.

Services for people with learning disabilities

A recent body of research has investigated the nature of service provision for adults with learning disabilities. Some studies have included in their sample, small percentages of people with disabilities from black and minority ethnic communities (e.g. Beresford, 1995; Emerson & Hatton, 1996). These studies have suggested the possibility of a difference between black and minority ethnic people with learning
disabilities and their families and white families in similar circumstances.

Beresford (1995) conducted a study exploring the circumstances of 1142 families caring for a disabled child at home. It was found that awareness and uptake of services was high; carers had seen between 5 and 9 professionals regarding their son or daughter over the past 12 months. The majority of carers (82 per cent) were satisfied with the services they received. Although carers tended to be satisfied with the services they received, in general service provision did not adequately meet their needs. The study included a small number of minority ethnic families (7.2 percent) who, in comparison to their white counterparts, were more likely to be living in urban areas, to be on low incomes and to live in unsuitable housing. Moreover, they were less likely to receive support from extended family members and less likely to attend support groups. In addition, services were less likely to meet the needs of black and minority ethnic families than white families. This research identified a number of particularly vulnerable groups; these included: parents from minority ethnic groups, lone parents and those caring for someone with greater needs due to physical disabilities and behaviour problems. Beresford (1995) concluded that the additional problems of black families suggest that they may have great support needs and that these were not met. The next section will examine studies that have investigated the experiences with services and the needs of black and minority ethnic people with learning disabilities and their families.

Service use by black and minority ethnic communities

The CVS consultant agency (which provides a private consultancy service to the
voluntary and statutory sector) recently carried out an important research project exploring some of the issues raised above. The study was commissioned by the Department of Health and aimed to examine the needs and experiences of minority ethnic groups with learning disabilities, in addition to offering guidance on different aspects of ethnicity and health as regards this group (CVS, 1998). Two of the study objectives were to look at obstacles to an equitable service provision, and the type of service provision developed for black and minority ethnic people with learning disabilities, both within services and within the black community itself. The aforementioned issues were investigated by contacting all social service departments, community health trusts nation-wide and projects run by community, or voluntary agencies catering for the needs of black and minority ethnic people with learning disabilities. In line with previous research (e.g. Baxter et al, 1990; Nadirshaw, 1997), the study found that service awareness and receipt is much lower in minority ethnic communities than in white communities, and that minority ethnic communities perceive services as unwelcoming or inappropriate.

Three of the key elements identified by the CVS report (1998) as important in the provision of good family support were; home-based support, respite care, and support groups. Carers from black and minority ethnic families tended to be unaware of the range of services that were available and able to offer support. There was a low uptake rate of many services, including home-based support and respite care. This were possibly due to a lack of awareness, but also to a perception that such services could be inappropriate and not address the cultural needs of families. Black and minority ethnic carers were less likely than their white counterparts to be members of and attend support groups. The CVS report (1998) concluded that
families from black and minority ethnic communities caring for their learning disabled offspring in the home setting, may be under acute pressure in their caring role, but may be reluctant to utilise the available support services.

The CVS report (1998) indicated that some black voluntary sector organisations appeared to be better than some of the statutory sector agencies at meeting the needs of black and minority ethnic people with learning disabilities and their families. This has been documented in previous research on minority ethnic groups’ utilisation of both established voluntary organisations and the black voluntary sector (e.g., Ahmed & Webb-Johnson, 1995). Field & Jackson (1989) state that uptake by black and minority ethnic communities of the established voluntary sector services, are low despite demonstrated demand for these services. Many researchers view this as related to the fact that voluntary organisations do not cater adequately for the needs of black and ethnic minority communities (e.g. Ahmed & Webb-Johnson, 1995; Ahmad & Atkin, 1996; Atkin, 1996; Baxter et al, 1990; Field & Jackson, 1989; Nadirshaw, 1997). The importance of black voluntary organisations in meeting the social care needs of black people is well established (Atkin, 1996). The increasing number of community projects designed to meet the specific support needs of minority ethnic communities, is related to the lack of appropriate and adequate statutory and voluntary services for minority ethnic communities. Atkin (1996) argues that black voluntary organisations complement other forms of provision by providing services that mainstream statutory and voluntary organisations are unable or unwilling to provide.
Keman and Walker (1981) researched the service use of black people with learning disabilities and their families. They also interviewed black professionals involved in service delivery to explore to what extent they regarded services as available and appropriate for black people with learning disabilities. Families caring for an adult with learning disabilities were also interviewed to explore service awareness, availability and utilisation, in addition to carers’ attitudes towards the service delivery system.

Keman et al (1981) found that people with learning disabilities from African-American communities under utilised the available services. Moreover, most participants (professionals, service users and their families) reported that there were not enough services within the black community. Furthermore, professionals providing services commented that services available within the community were under used by black people, and that black families appeared either reluctant or unable to access and use services outside their own community. The views of these service providers are to some extent, in line with findings of previous research and reports indicating that black families with a learning disabled member, are less likely to use the available services than their white counterparts (Justice, O’Connor & Warren, 1971; Schild, 1976). Justice et al (1971) found that 79 per cent of white families with a learning disabled member used the available services, in contrast to 19 per cent of black families. Justice et al (1971) argued that the main reason for low service uptake within the black community was a lack of awareness of the available services. Keman et al (1981) found a similar lack of awareness in their study and reported that only 25 per cent of the families they interviewed were aware of the available services. In addition, 45 per cent of those who were aware of the available
services, learnt about them through informal sources such as, friends, neighbours or members of the church they attended and not through the efforts of the services concerned.

Keman et al (1981) argue that attempting to obtain appropriate services for people with learning disabilities can in itself be frustrating and defeating, especially if families do not adequately 'know their way around' the often confusing and complicated service systems, and argued that many families abandoned trying after a while. This is an important point, given the possible complications of the care management and needs assessment processes in the UK, coupled with the lack of black advocates and independent care managers to help black and minority ethnic people with learning disabilities. Keman et al (1981) also found that black families were distrustful of services and felt that they were discriminated against by white services, believing that professionals treated them as black first and people in need of services second. Many families felt that white professionals had little understanding of cultural differences and were therefore discouraged from seeking services which they felt were likely to be inappropriate to their needs.

Keman et al (1981) concluded that it is important for people from all communities to be informed about the available services and know about the way in which services can benefit them. Services should also be sensitive to the needs of black people with learning disabilities, and their families, who may in turn become more confident about using them. Keman et al (1981) suggest a system of advocacy to help families and people with learning disabilities to better access much needed services. Although the research by Keman et al (1981) made some important contributions to the debate
in this area, it is now rather dated; there is a need for more current research to explore the experience of black people with learning disabilities. Also, as the above study was carried out in the USA, its generalisability to the British context is questionable.

The next section will focus on a recent British study that explored the service use and experiences of Asian families caring for someone with learning disabilities in the home setting. Azmi, Hatton, Caine & Emerson (1996) studied 54 Asian families caring for an adult with learning disabilities in the home setting in two boroughs of north-west England. Azmi et al (1996) found that there was a high level of need for services within this community and that many of these needs were not being met by the available services, both within statutory and voluntary organisations. This is a similar profile to that observed in Asian communities in Bradford (ADAPT, 1993).

The Azmi et al (1996) study found that almost all adults with learning disabilities in their sample lived at home with their families and most main carers were mothers who were born outside the UK and spoke limited English. Therefore, there were significant communication barriers between Asian carers and the English speaking services. Many families experienced considerable economic hardship and social deprivation, as measured by household income, employment status, and the location and standard of housing. Seventy-five per cent of households had no full-time wage earner and 87 per cent reported experiencing financial difficulties. Adding to the difficulties inherent in the caring role, a significant number of mothers were caring for two or three offspring with learning disabilities. It was also found that a substantial proportion of these families was caring for individuals who had
significant support needs, in terms of self-care and management difficulties. Although fifty-three percent of people with learning disabilities had challenging or problem behaviours, when families were asked about the quality of the services they received, 41 per cent of carers reported that they were not receiving enough services to be able to comment (Azmi et al, 1996).

As with other studies about the service use of black and minority ethnic communities, the Azmi et al (1996) study found that there was a general lack of awareness of the specialist health and social services available to people with learning disabilities and their families. Although almost all carers were aware of general health and welfare services, very few were aware of the specialist health and social services for people with learning disabilities. This was also reflected in service use, most people with learning disabilities used the general health and social services but few were in contact with, or used specialist services.

It was found that carers who could speak and write English tended to be more aware of the range and variety of services available. In addition, it appeared that carers in wealthier households had been resident in the UK longer and were more likely to receive services than their less well off counterparts, who in general had been resident in the UK for shorter periods of time. When asked to comment on the services they received, both carers and people with learning disabilities felt that services in general were not appropriate to meet their needs. One reason reported was that staff was not sensitive to the cultural needs of Asian service users; this was particularly true of respite services. Most Asian service users attended a range of day services and most of their carers rated day services as sufficient in quantity, although
ratings of the quality of these services varied. Participants mainly criticised the lack of culturally appropriate service practices (Azmi et al, 1996).

Asian people with learning disabilities markedly under-utilised residential and respite care services in comparison to families from the indigenous population. It was found that only 23 per cent of families used this service; other studies of people with learning disabilities found that the indigenous population received twice this amount of respite care (e.g., Evans et al, 1994). Many carers from the Azmi et al (1996) study felt that respite services were insufficient in quantity and that the quality of these institutions was variable.

The carers who participated in this study were under a great deal of pressure; many of them were caring for someone with high support needs with little support from services, resulting in 80 per cent of carers reporting symptoms of stress indicative of psychiatric distress. The degree of distress in this population is higher than that reported in any other study of carers of people with learning disabilities (e.g. Sloper & Turner, 1991; 1994; Kieman and Alborz, 1994). Azmi et al (1996) found that carers on very low incomes and caring for more that one individual with learning disabilities tended to experience the greatest degree of stress. Many carers reported stress-related emotional and physical problems and visited their GP more often than the national average. The majority of service users had experienced stigma and racial abuse from people in their neighbourhood, as well as from other service users and members of staff in service settings.

Azmi et al (1996) asked carers for their opinions about how services could be
improved. These fell into three main categories: (1) improving communication (e.g., the provision of information presented in appropriate languages and formats), (2) increasing the cultural sensitivity of services (e.g., the recognition and celebration of religious festivals) and (3) more flexibility in service response (e.g., the provision of short-term family placements with other Asian families).

In summary, the study by Azmi et al (1996) suggests the presence of a high level of need for services within the Asian community. However, many of these needs were not being met by the available services, both within statutory and voluntary organisations. Carers were experiencing high levels of stress, due to a lack of either formal or informal support, which could put them at risk of developing mental health problems. People with learning disabilities had experienced racism, not only in their local area, but also at the hands of other service users and staff. This appeared to be an important reason for their reluctance to use some of the services.

ISSUES FOR INVESTIGATION

The current study was inspired by the Azmi et al (1996) study; and aimed to replicate its findings and to investigate their generalisability to other minority ethnic groups. Specifically, families from African/Caribbean backgrounds caring for an adult with learning disabilities in the home setting will be studied. This study will utilise a structured interview method to explore the following areas: characteristics of the families and their current living circumstances, service awareness and receipt, satisfaction with and confidence in services, barriers to service uptake and means of improving access to services. In addition, the level of stress experienced by carers
and the sources of support they utilise will be explored.

Family circumstances

It has been documented that black and minority ethnic people face substantial disadvantage when compared to their white counterparts. Beresford (1995) reported that, in comparison to white families caring for a child with disabilities, black families are more likely to be on lower incomes and to live in inadequate housing. Azmi et al (1996) found that many Asian families were living in circumstances of material deprivation. These factors can cause stress and result in added pressure on families caring for someone with learning disabilities. This study will explore whether the circumstances of African/Caribbean families are similar to those of Asian families.

Service awareness and receipt

A large body of research illustrates that black and minority ethnic communities have low uptake rates of the available mental health services (e.g. Ahmed & Webb-Johnson, 1995; Fernando, 1991; 1995; Soni Raleigh, 1995). A similar picture has been observed with respect to black and minority ethnic communities’ use of learning disabilities services (e.g. Begum, 1995; Nadirshaw, 1997). Many reasons have been put forward to account for the low service uptake observed within these communities, most importantly the lack of awareness about the available services within black and minority ethnic communities. Minority ethnic families tend to be less aware of the available services than families from the indigenous population in
similar circumstances (e.g., Azmi et al, 1996; Baxter et al, 1990; Evans et al, 1994). Receipt of services also tends to be lower in minority ethnic families, when compared to white families (ADAPT, 1993; Beresford, 1995; Evans et al, 1994). This study will investigate service awareness and use among African/Caribbean families, with a view to exploring the relevance to this population of research into black and minority ethnic peoples' use of mental health and learning disabilities services.

** Satisfaction with and confidence in services **

Lack of satisfaction with, and confidence in services have been found to be important factors contributing to the under-utilisation of services within black and minority ethnic communities (e.g. Baxter et al, 1990; CVS, 1998; Fatimilehin et al, 1998; Kernan et al, 1981). Both mental health and learning disabilities services seem to have considerable difficulty with meeting the needs of black and minority ethnic communities (e.g. Atkin & Rollings, 1996; Azmi et al 1996; Baxter et al, 1990; Fatimilehin et al, 1998; Fernando 1995). Moreover, people from black and minority ethnic communities often regard services as inappropriate and have little confidence in services' ability to meet their needs (e.g. CVS, 1998). In this study, confidence in and satisfaction with services will be examined with regards to a group of carers from African/Caribbean communities caring for an adult offspring at home.

** Barriers to service uptake and means of improving access to services **

The literature indicates that there are many barriers for people from black and
minority ethnic communities to accessing appropriate services. These barriers include: poverty and racial inequalities (Ahmad et al, 1996); lack of understanding within services of the cultural needs of people from black and minority ethnic communities, for example, not providing for the different dietary needs that exist (e.g. Baxter et al, 1990; Nadirshaw, 1997); lack of awareness of the available services within black and minority ethnic communities (Azmi et al, 1996; CVS, 1998; Keman et al, 1981). The lack of culturally appropriate practices within service provision and racial discrimination within services are also likely to discourage use by people from minority ethnic communities (Azmi et al, 1996; Baxter et al, 1990; Nadirshaw, 1997).

Fatinmilehin et al (1998), along with other researchers (e.g. Fernando, 1995; Keman et al, 1981), have argued that people from black and minority ethnic communities can sometimes mistrust services; this may or may not be based on negative past experiences. It has been suggested that some of the existing barriers to service uptake can be overcome by: increasing awareness by providing information in mediums and places where it will be accessible; providing services that are appropriate and meet the cultural needs of all users not just those from the indigenous population (Azmi et al, 1996, Baxter et al, 1990, CVS, 1998; Nadirshaw, 1997; Shah, 1995). In this study the opinions of African/Caribbean families will be sought as regards to barriers to service uptake along with their views about improving access to discover whether previous findings are relevant to this population.
Level of stress experienced by carers

A number of studies have report increased levels of stress among parents of children with learning disabilities in comparison to those who do not have children with learning disabilities. A study by Carpiniello, Piras, Pariante, Carta and Rudas (1995) found that parents of disabled children suffered from higher levels of stress and psychiatric symptoms than those without. Although other studies have not found higher levels of stress in families caring for a learning disabled person (Byrne & Cunningham, 1985), the majority of studies suggests that mothers of learning disabled children do experience higher levels of stress (Wikler, 1981).

Beckman (1983) found that single mothers experienced more stress than married mothers did, and Bradshaw & Lawton (1978) found that lower income was related to stress. Research also suggests that characteristics of the child, and higher levels of physical dependency (e.g. Tew & Lawrence, 1975) and behavioural problems (e.g. Chetwynd, 1985) can be associated with high stress levels in parents. Seltzer & Krauss (1989) found that a number of factors were related to high levels of stress in parents caring for their adult offspring in the home setting; these included: marital status, income, the level of learning disabilities of the person being cared for, and physical dependency of the disabled person. Grant & McGrath (1990) found that a range of factors could cause stress for parents, financial difficulties being one of the most important. In addition, the level of support parents receive, together with the physical dependency of the person with learning disabilities and the level of his/her challenging behaviour can cause stress for parents (Grant & McGrath, 1990). Research has also shown that some factors can act as buffers against stress, for
example, the resources and support families have at their disposal. A study by Dunst, Trivette & Cross (1986) suggested that informal and formal support resources could buffer against stress.

Therefore, although the data are equivocal, the results of a number of studies indicate that a range of factors can be associated with stress. Azmi et al (1996) found a very high level of stress in Asian families caring for someone with learning disabilities. These families also experienced a number of the factors that have been found to be associated with increased levels of stress. The CVS report (1998) and other research suggests that black and minority ethnic parents caring for someone with learning disabilities may be experiencing acute levels of stress. This study will explore whether the same picture emerges among African/Caribbean carers looking after an adult son or daughter with learning disabilities in the home setting.

Due to the dearth of information into the experience of African/Caribbean people with learning disabilities and their families, there is a need to focus research on their experience of service use, and the support needs of this group. This information would be very useful for service providers and professionals working with people with learning disabilities from African/Caribbean backgrounds and their families, as it could help them to think about future satisfactory and culturally appropriate service provision for this group.

**Research Aims**

The study will examine the family circumstances and characteristics of a sample of
African/Caribbean families caring for an adult with learning disabilities in the home setting. It will ascertain the type and levels of services used, and explore carers’ experiences of, and views about the services used, in addition to examining levels of carer stress and factors associated with stress.

Specifically the following questions will be addressed:

1. To what extent are African/Caribbean carers aware of the available statutory sector services for people with learning disabilities?
2. What types of statutory sector services do these families use and to what extent?
3. What factors are associated with service awareness and receipt?
4. What are carers’ perceptions and views of the services being used? Specifically, what factors are associated with satisfaction with services?
5. What are the levels of stress amongst this group of carers?
6. What factors are associated with higher levels of stress?
Chapter Two

METHOD

Overview

Twenty-nine African/Caribbean parents/carers caring for an adult son or daughter with learning disabilities at home were interviewed about the amount and types of services used by the family. The researcher visited the carers in their homes to conduct a structured interview, which consisted of a battery of five questionnaires. Interviews focussed on, service awareness and use and factors associated with this, in addition to carers’ experience of, and opinions about the services being used. General levels of carer stress and stress related more specifically to the caring role were also explored.

Recruiting the sample

Participants were identified and recruited from local statutory and voluntary services in three boroughs of Greater London. Although a variety of organisations were contacted, participants were recruited from Health and Social Services community learning disabilities teams and local MENCAP services only. A letter was sent to a key person in each organisation. This letter introduced the researcher, provided brief details about the study and suggested a meeting to discuss the study further. The aforementioned letter was then followed up by a telephone call. The researcher met
with a key person in each organisation and then attended meetings with managers and team members to outline the study and to seek permission to make contact with potential participants.

The researcher contacted prospective participants in one of two ways, either directly, or through a liaison person within each organisation. The researcher wrote to those individuals who had been identified as appropriate by the organisations and subsequently telephoned them to outline the study and invited them to participate. Due to issues of confidentiality some organisations, both statutory and voluntary, did not feel it was appropriate to disclose information about service users or their carers. Therefore, the information about the project was given to the liaison person in the organisations to be sent out. It was then left up to individuals to reply to the researcher or the organisation if they wished to participate in the study; it was only at this stage that a given organisation supplied individuals’ personal details. The researcher then telephoned each respondent and gave him or her further details of the study and arranged a time to visit him or her at home to conduct the structured interview.

All carers were sent two letters, a covering letter from the statutory or voluntary organisation introducing the project and the researcher and a second letter from the researcher describing the project, explaining what would be required from participants and the potential usefulness of the project (see Appendix 1). An information sheet giving brief details about the study and a reply slip with a stamped addressed letter to be sent back to the researcher or organisation were also included in the pack.
A pilot study of two African/Caribbean parents caring for an adult with learning disabilities was carried out prior to contacting carers. This was conducted to test the feasibility of the study, and the reliability/validity of one of the measures (i.e., the questionnaire on the use of day care and respite care) which, has been recently used with another minority ethnic group. Following the pilot study two areas of the aforementioned questionnaire were adapted to make them more relevant to the minority ethnic population to be investigated.

A total of 74 letters were sent out to potential participants in the three different geographical areas; five individuals were contacted more than once via the different organisations leaving 69 potential participants. Four (six per cent) could not be contacted, six (nine per cent) were unsuitable (e.g., people with learning disabilities were too young or no longer living at home). Three carers (four per cent) refused to participate, two carers (three per cent) initially agreed to be interviewed but later cancelled due to health concerns, and 25 (36 per cent) did not respond despite reminders being sent out to them by the organisations. The remaining 29 carers (42 per cent) participated in the study.

The response rate from appropriate individuals varied greatly depending on the recruitment method used. A response rate of between 73 per cent and 89 per cent was obtained when the researcher contacted carers directly. However, a response rate of between five per cent and 40 per cent was obtained when carers were contacted by services on the researcher’s behalf.
Participants

Participants were 29 primary carers from African/Caribbean backgrounds looking after a son or daughter with learning disabilities in the home setting. There was no upper age limit for carers, but they were required to be caring for someone who was 19 years or older and were therefore using adult services. All carers were fluent in English; this consideration was due to the time and resource constraints of this study.

Twenty-eight of the 29 primary carers interviewed (96.5 per cent) were the mothers of the person with learning disabilities and one was the father. The average age of carers was 57 years old (range 38 to 77 years old, SD 8.75). Just over a third (ten, 35 per cent) were married, seven (24 per cent) were divorced, five carers (17 per cent) were single, four (14 per cent) were separated and three (ten per cent) were widowed. No carers described themselves as 'cohabiting'. The majority of carers (93 per cent) were caring for one adult son or daughter with learning disabilities. Two carers (seven per cent) were looking after two adult children with learning disabilities; however, details on the eldest sibling only will be reported in this study.

Of the adults with learning disabilities being cared for sixteen (55 per cent) were male, and 13 (45 per cent) were female. The mean age was 28 years (range 19 to 40 years, SD 6.10). Carers reported that their children had a number of conditions associated with learning disabilities. Five people (17 per cent) had downs syndrome, three (10 per cent) had cerebral palsy, nine (31 per cent) were autistic, and five (17 per cent) suffered from epilepsy. In addition, four people (14 per cent) had visual
impairments, four people (14 per cent) were hearing impaired, and seven people (24 per cent) were reported to have a psychiatric disorder.

**Ethical considerations**

Ethical approval for the study was granted from three committees, the UCL/UCLH research committee, the Camden and Islington Community Health NHS Trust committee, and the Brent Medical ethics committee (see Appendix 2 for letters of approval). The letters inviting carers to participate briefly outlined the study and the information sheet that was sent with the letters, informed carers that taking part or not taking part in the study would not affect any services their son or daughter was currently receiving. The information sheet also stated that all information given to the researcher would be kept confidential (see Appendix 3).

Before each interview commenced, each carer was requested to sign a consent form (Appendix 3). Carers were informed that they would receive a summary report of the study in due course if they wished to have one. In addition, the telephone number of a contact person within each of the community learning disabilities teams and the MENCAP services was made available to carers should they require further information or advice.

**Procedure**

The researcher visited each participant in their home, the aim of the study and issues of confidentiality were reiterated at the start of the interview. Although the interview
was conducted with the primary carer, carers’ partners were also invited to participate. Carers were invited to ask any questions they might have before signing a consent form. The interview lasted between 75 and 120 minutes and followed a standard sequence (see Appendices 4 to 9 for the full interview schedule). Five questionnaires made up the interview schedule, exploring carer awareness, receipt and experiences of using services; use and views about day care and respite care; the level of disability and support needs of the adult being cared for; levels of stress being experienced by carers generally, and stress related more specifically to the caring role.

When it was necessary the researcher remained after completion of the interview to listen to participants who became distressed or upset whilst talking about their experiences. This was done in a manner that was both sensitive about participants’ feelings and diplomatic about services.

Measures

The interview schedule used followed closely that used in the Azmi et al (1996) study on service use among Asian families caring for a relative with learning disabilities. However, in this study the Short-form of the Questionnaire on Resource and Stress was also utilised (Friedrich, Greenberg, and Crnic, 1983).

Disability Assessment Schedule (DAS: Holmes, Shah & Wing, 1982)

The DAS (Appendix 4) is a schedule which involves conducting a structured interview with an informant who knows the person with learning disabilities well; in
the present study this was the primary carer. The DAS was designed to elicit information on the pattern of impairments, abilities and behaviour problems exhibited by adults and children with learning disabilities. This instrument consists of eight sections, comprising two broad domains, physical and developmental skills and behavioural abnormalities. Each section includes two or more items that are rated between 3 to 8 points. The higher the score across sub domains (e.g., behaviour problems) as well as the score on the total domain, the higher the level of functioning of the person with learning disabilities. For the present study items relating to physical, and some developmental skills along with behavioural abnormalities were used. The sections used fell under the following domains: mobility, continence, self-help, communication, domestic skills, literacy, and behavioural and medical problems.

The DAS was preferred to other instruments because it is a comprehensive measure of ability and disability in people with learning disabilities. Holmes et al (1982) developed this scale by modifying a number of earlier scales, the Wessex Speech, Self-help and Literacy Scale (SSL, Kushlick, Blunden, and Cox, 1973); and the Children's Handicaps, Behaviour and Skills (HBS) structured interview schedule (Wing & Gould, 1978). Unlike other scales such as the SSL and the Vineland Maturity Scale (Doll, 1965), the DAS incorporates items on impairment of non-verbal communication and social interaction, in addition to a wide range of common behavioural problems. As the DAS is a brief screening assessment scale, it can be administered relatively rapidly. Although there are other comprehensive measures of abilities and disabilities for people with learning disabilities (e.g., the Adaptive Behaviour Scale), these scales can require in excess of one hour to administer. The researcher felt that it would not be feasible to include within the battery of measures
used, larger scales, as these would have at least doubled the length of the interview. The DAS has also been used extensively in previous studies with people with learning disabilities.

The developers, Holmes et al (1982) have conducted extensive tests of reliability. The reliability of the DAS was tested in a number of different ways. Generalisability across occasions: (1) Test-retest using the same informant at different times (reliability coefficient ranging between 0.83 and 0.99). Generalisability across observers: (2) Researchers interviewed different informants in the same setting (e.g., hospital ward) and correlated the agreement between staff (reliability coefficient ranging between 0.77 and 0.95); (3) Researchers interviewed different staff members in different settings (e.g., hospital ward and day centre) and correlated the agreement between them (reliability coefficient ranging between 0.44 and 0.87). Finally inter-rater reliability tests were also conducted and a reliability coefficient of 0.76 and 0.94 was found.

The aforementioned assessments suggests that the DAS has adequate reliability as a measure of impairments, ability and challenging behaviour in people with learning disabilities (Holmes et al, 1982). However, there are no extensive evaluations of the validity of this scale (Quine, 1986).

The Client Service Receipt Interview (CSRI: The Personal Social Services Unit, University of Kent, 1990)

The CSRI (Appendix 5) records the range of services of which the user or carer is aware and records, in some detail, use of services over a period of time (in the
present study over the past 6 months). It enquires about the frequency of service use and duration of sessions with professionals. Services represented in this instrument includes general health, social services and specialist services, such as those commonly found within multi-disciplinary teams; for example, community nurses, psychologists, speech and language therapists, occupational therapists etc. The CSRI records satisfaction with the range of services being used, in addition to carers’ perceptions about barriers to obtaining these services.

This instrument has been used extensively in previous research (e.g. Beecham & Knapp, 1992; Knapp & Anderson, 1990; McCrone, Beecham & Knapp, 1994) and primarily with recipients of mental health services specifically. It has been used mainly by health services to estimate the cost of services used by patients with enduring mental illness rather than in psychological research. As with most such ‘economic instruments’ the reliability and validity of the CRSI has not been formally addressed. However, the researcher felt it would generate useful information about the study’s main areas of interest i.e., what services carers were aware of, and which ones had been used over the previous six months. An alternative might have been to ask open-ended questions about the services carers knew about and used; however, it was felt that more comprehensive information would be gained from using this checklist rather than relying on carers’ memory alone.

Recently Azmi et al (1996) adapted the CRSI and used it to assess services used by people with learning disabilities. As this study intended to replicate the Azmi et al (1996) study at least to some extent, it was felt that it would be important to use the same measures employed in the aforementioned study. Therefore, the version of the
CSRI adapted by Azmi et al (1996) was used in this study.

**Questionnaire on the use of day care and respite care (Azmi, Hatton, Caine & Emerson 1996)**

The questionnaire on the use of day care and respite care (Appendix 6) was adapted from that devised by the Hester Adrian Research Centre (Azmi, Hatton, Caine & Emerson, 1996), and used in the recent Azmi et al’s (1996) study. This schedule involves conducting a structured interview with the carer of the person with learning disabilities and was designed to elicit information about the types and quantity of day care and respite care used. In addition, this instrument elicits the views of carers about the quality and sufficiency of day and respite care, and about how these services can be improved. This schedule also includes questions on the health status of carers and the impact of caring for someone with learning disabilities on carers’ health.

Information relating to day and respite care is elicited primarily in two ways:

1. Carers are asked to choose from a list of predetermined items, for example, with respect to the question “What type of day care does...........receive currently?” the carer is asked to choose one or more of the following items:

   - Adult training centre/special education centre
   - Hospital unit
Carers employed
Further education
Other (specify)
Receives none

2 carers are asked to respond “yes” or “no” to questions; for example

“Are there arrangements (in day care services) that are in any way culturally specific?”

Information on how services can be improved were elicited by asking carers to choose one or more statements from a list; for example, with respect to the question “In your opinion how can the day care services be improved?” the carer is asked to choose one or more of the following:

- Appropriate day care activities that are culturally relevant (give examples)
- Appropriate dietary requirements
- More African/Caribbean staff
- Staff from any cultural background who must be sensitive to the specific cultural needs of users
- Provision of single sex day care services
- Other (please specify)

Information about the impact of caring for someone with learning disabilities is
elicited in a number of ways. There are questions on the emotional and physical effects of caring to which the carer is asked to respond by choosing between a number of statements; for example to the question "Do you feel that looking after............. is affecting or has affected your health, physically or in a mental or emotional sense?" the carer is asked to choose one of the following:

- No reported effect on health
- Physical health only
- Mental/emotional health only
- Physical and mental/emotional health

To date only the developers, Azmi, Hatton, Caine & Emerson (1996) have used this measure; therefore there are no data available on the validity and reliability of this measure as yet. However, the questionnaire on the use of day care and respite care was chosen for use in the present study because it assesses the level of use of two important services for people with learning disabilities. In addition, this measure includes items on cultural issues related to the use of day and respite care. The researcher also felt it was important to use the same measures as used in the Azmi et al (1996) study on which the current study has been based.

**The Malaise Inventory (MI: Rutter, Tizard & Whitmore 1970)**

The MI (Appendix 7) assesses the level of stress being experienced by an individual and is a 24 item binary choice questionnaire (range 0-24). The MI enquires about some physical/psychosomatic and emotional states usually associated with stress.
Carers were asked to answer 'yes' or 'no' to questions such as: 'Do you often feel miserable and depressed?' 'Do you often get worried about things' The MI has a cut-off score of 6 or greater, whereupon an individual is considered to be at risk of developing psychiatric problems.

The MI was adapted by Rutter, Tizzard & Whitemore (1970) from the Cornell Medical Index in order to assess stress levels in parents. Stress was defined as emotional disturbance and a decrease in mental well being. The scale has been extensively used to assess stress levels in parents and carers of non-disabled children (e.g., Fanshawe, 1986; Rutter, Graham & Yule, 1970). In addition, it has been widely used to assess stress levels in parents and carers of children and adults with learning disabilities (e.g., Bradshaw & Lawton, 1978; Cooke et al, 1982; Gath, 1977; Quine & Pahl, 1985; Quine, 1986).

The scale enquires about physical/psychosomatic states and emotional states commonly associated with stress. As this scale attempts to measure such a multifaceted concept as stress, it is open to criticism. Bradshaw et al (1978) argue that it is possible that the scale does not adequately cover some of the physical symptoms associated with stress (e.g., ulcer and skin complaints). However, this instrument was chosen for the current study because it is one of the most widely accepted scales of its type and considered to be one of the best available to assess stress (Bradshaw et al, 1978).

The MI has been the subject of a large amount of evaluation (e.g., Cooke et al, 1982; Hirst & Bradshaw, 1983). The reliability of the MI has been demonstrated in various
studies. Rutter et al (1970) found a test re-test reliability coefficient of 0.91, although it was found that mothers tended to report fewer symptoms at the second testing. Quine (1986) demonstrated a test re-test reliability coefficient equal to 0.94, confirming the pattern of reliable results shown by Rutter et al (1970). Bradshaw et al (1978) found a test re-test reliability coefficient of 0.96 in their study and follow-up of 17 families caring for a disabled offspring. Quine and Pahl (1985) in their study of families caring for a severely disabled child, found a test re-test reliability coefficient of 0.94, again confirming that the measure has adequate reliability.

Cooke et al (1982) calculated the MI scores obtained in their study in three different ways, comparing each score with others on the MI and also comparing MI scores with scores derived from the Symptom Scale. They found very little difference whichever scale was used, all correlating closely. In a study of 200 families with children with severe learning disabilities and behavioural problems, Quine et al (1985) found a highly significant association between maternal malaise scores and mental health ratings as measured by the Symptom Scale. Although no figures were quoted to substantiate Quine et al’s (1985) findings, the information described in the two studies mentioned here appear to indicate that the MI has reasonable validity when employed to assess the stress levels of parents of people with learning disabilities.

Short-form of the Questionnaire on Resources and Stress (QRS-F: Friedrich, Greenberg & Crnic, 1983)

The QRS-F (Appendix 8) measures the impact of a learning disabled, physically
disabled or chronically ill person on family members. This is a 52-item scale, which comprises 4 sub-scales: parent and family problems, child characteristics, carer pessimism and physical incapacitation. Each item consists of statements to which the respondent answers either 'true' or 'false'. For example, the items 'I get upset with the way my life is going' and 'I have given up things that I really wanted to do in order to take care of__________' A response of 'true' to the above items is scored 1 and 'false' is scored 0. Scores range from 0-52, the higher the scores across sub-scales and the total score, the higher the level of carer stress.

This measure was chosen to assess the impact of caring for an individual with learning disabilities in the family setting and specifically, stress related to the caring role. Many researchers have recognised and documented the fact that parenting children with handicaps results in significant amounts of unique familial stress (e.g., Blacher, 1984; Farran Metzger, & Sparling, 1986; Fewell, 1986). The measure was chosen because it is one of the most frequently used to measure stress in families of children with handicaps and has been shown to have promising psychometric properties (Scott, Sexton, Thompson & Wood, 1989).

Data available on the psychometric properties of the QRS-F suggests that it has adequate reliability. The results of Friedrich et al (1983) analyses suggest that the internal consistency of the questionnaire is high (coefficient alpha 0.95). A later study conducted by Scott et al (1989) found a similar level of reliability (coefficient alpha 0.92). Scott et al (1989) found that the reliability of the QRS-F was roughly the same when used with parents of children with handicaps (coefficient alpha = 0.88), and when used with parents of children without handicaps (coefficient alpha = 0.89).
These results suggest that this measure can be usefully employed in comparison studies as well as experimental studies.

The validity of the QRS-F has also been assessed. Scott et al (1989) conducted an analysis to ascertain the sources of variance in the QRS-F. Scott et al (1989) analysed data from parents of 66 disabled and 66 non-disabled children, using the variable of parental sex to analyse the sources of variance. The substantial variance was found to be in scores associated with families having children with or without handicaps and not associated with the sex of the parent. Correlations between mothers' and fathers' scores were found to be 0.67 (p<001). This suggests that the QRS-F has reasonable construct validity.

Friedrich et al (1983) conducted a correlation matrix of the four QRS-F sub-scales (e.g., parent and family problems, pessimism), with other independent measures of constructs that the different sub-scales are considered to be related to (e.g., Beck Depression Inventory, the Marlowe Crown checklist of social desirability and the Problem Checklist). Friedrich et al (1983) describes significant correlations between the four sub-scales and the independent measures. Although no figures were quoted to substantiate Friedrich et al’s (1983) findings, the information described here suggests that the QRS-F has reasonable validity.

**Demographic Characteristics**

In accordance with previous literature, information on a range of demographic characteristics (Appendix 9) of both the carer and the person with learning
disabilities being cared for were collected, including:

1. Age of the carer,
2. Age of the person with learning disabilities,
3. Ethnic origin of family,
4. The number of years the carer has been resident in the UK,
5. Physical health of the carer,
6. Physical health of the person with learning disabilities,
7. Whether the carer is employed,
8. Whether the carer’s partner is employed (if applicable),
9. Household income,
10. Benefits received,
11. Status and standard of housing (whether adequate or inadequate),
12. Whether families experience financial difficulties,
13. The diagnosis of the person with learning disabilities.
Chapter Three

RESULTS

The aim of the study was to identify a sample of African/Caribbean families caring for a learning disabled adult offspring in the home setting and to explore the characteristics of the carers and person being cared for. The study also aimed to examine the type and level of service awareness and receipt in the sample. The results will be presented in five sections; section one will focus on the sample’s demographic characteristics and present some related descriptive statistics; section two will explore carers’ awareness and receipt of services as well as the factors associated with awareness and receipt; section three will investigate carers’ perceptions of the services that are used; section four will identify the levels of stress among these carers and the factors associated with carer stress; finally section five will summarise the main findings of the study.

PARTICIPANTS’ DEMOGRAPHICS

Characteristics of carers

To ascertain the characteristics of the families in the sample and explore their living circumstances, descriptive analyses were conducted. Twenty-nine primary carers were interviewed; 28 (96.5 per cent) were the mothers of the person with learning disabilities and one was the father. The mean age of carers was 57 years old (range 38 to 77 years old, SD 8.75). Almost all carers (28 carers, 96.5 per cent) had been
born outside the UK, but had lived in the UK for a mean of 31 years (range 10 to 48 years, SD 11.50). The majority of carers were from the Caribbean (19 carers; 66 per cent); most of the remaining carers were from Africa (seven carers; 24 per cent). Two carers (seven per cent) described themselves as ‘black other’. One carer (three per cent) was born in the UK and described herself as ‘black British’. Over half of the main carers (55 per cent) considered themselves to have health problems, rating their health as “poor” or “fair”. However, this did not appear to be reflected in the number of times carers had visited their GPs over the past twelve months, as 79 per cent of carers in this sample had had 4 or below visits to the GP. The mean number of health problems reported by carers was four (range zero to ten).

The majority of households consisted of single parent families (19 carers, 65 per cent), due to divorce, separation, death etc. Two-parent families accounted for 35 per cent of the households (ten families). A large number of houses (13 houses, 45 per cent) were owner occupied, but a high proportion of families rented their properties from the council (ten houses; 35 per cent). The majority of the remaining houses were rented from housing associations (five houses 17 per cent). With one house (three per cent) only being privately rented. Houses were relatively small (median: six rooms per house, range: four to eight rooms). The level of household yearly income in the sample was relatively low, with two-thirds of the sample receiving less than £10,000 income per year (19 households, 66 per cent). A small proportion of carers (four carers, 14 per cent) were not prepared to disclose the family’s yearly income, therefore there is no data for this group. The majority of carers (20 carers, 69 per cent) reported experiencing financial difficulties. A large number of carers (19 carers, 65 per cent) reported experiencing difficulty with meeting bills or other
financial commitments, with 34 per cent reporting either "marked difficulty" or "severe difficulty". Table 1 presents carer ratings of housing adequacy, levels of household income and the extent of difficulty with paying bills.

Table 1

Carer ratings of housing adequacy, household income and difficulty paying bills

<table>
<thead>
<tr>
<th>Housing Adequacy</th>
<th>Number of carers</th>
<th>Per cent of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate</td>
<td>16</td>
<td>55</td>
</tr>
<tr>
<td>Slightly inadequate</td>
<td>7</td>
<td>24</td>
</tr>
<tr>
<td>Moderately inadequate</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Severely inadequate</td>
<td>3</td>
<td>10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Levels of annual household income</th>
<th>Number of carers</th>
<th>Per cent of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than £10,000</td>
<td>19</td>
<td>66</td>
</tr>
<tr>
<td>£10,000 - £20,000</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>£20,000 - £30,000</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Over £30,000</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Difficulty in paying bills</th>
<th>Number of carers</th>
<th>Per cent of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>No difficulty</td>
<td>10</td>
<td>35</td>
</tr>
<tr>
<td>Slight difficulty</td>
<td>9</td>
<td>31</td>
</tr>
<tr>
<td>Marked difficulty</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Severe difficulty</td>
<td>4</td>
<td>14</td>
</tr>
</tbody>
</table>

The majority of primary carers did not have employment outside of the home, with 14 carers (48 per cent) under retirement age spending their time caring for their learning disabled offspring. A large portion of carers were of retirement age (12 carers, 41 per cent). Of the ten primary carers who had partners, four (ten per cent)
were employed; in total only seven families (24 per cent) had a full or part-time wage coming into the home. A substantial proportion of families (22 families, 76 per cent) were relying on benefits and pensions as their main source of income. The majority of carers (20 carers, 69 per cent) viewed their finances as to some degree inadequate for the family’s needs, with forty-five per cent rating their finances as either “markedly inadequate” or “severely inadequate”.

Characteristics of people with learning disabilities (PWLD)

Of the 29 people with learning disabilities being reported on here, 16 (55 per cent) were male, and 13 were female (45 per cent), with a mean age of 28 years (range 19 to 40 years, SD 6.10). The level of disability of the person being cared for was assessed using the Disability Assessment Schedule (DAS). There was some variability in terms of self-help skills in the sample. However, most people appeared to be experiencing severe difficulties with everyday skills, e.g. communication and cognitive abilities. In order to discover the severity and types of disability in the PWLD being cared for, descriptive analyses were conducted on DAS scores. The results are presented in Table 2.
Table 2
Number of people in each category of disability as measured by the DAS

<table>
<thead>
<tr>
<th>Category of disability</th>
<th>Number (Per cent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>4 (10)</td>
</tr>
<tr>
<td>Continenence:</td>
<td></td>
</tr>
<tr>
<td>Night wetting</td>
<td>8 (28)</td>
</tr>
<tr>
<td>Night soiling</td>
<td>8 (28)</td>
</tr>
<tr>
<td>Day wetting</td>
<td>14 (48)</td>
</tr>
<tr>
<td>Day soiling</td>
<td>11 (38)</td>
</tr>
<tr>
<td>Self-help:</td>
<td></td>
</tr>
<tr>
<td>feeding</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Washing</td>
<td>18 (62)</td>
</tr>
<tr>
<td>Dressing</td>
<td>11 (38)</td>
</tr>
<tr>
<td>Communication:</td>
<td></td>
</tr>
<tr>
<td>Method used</td>
<td>15 (52)</td>
</tr>
<tr>
<td>Understanding</td>
<td>14 (48)</td>
</tr>
<tr>
<td>Clarity of speech</td>
<td>15 (52)</td>
</tr>
<tr>
<td>Cognitive ability:</td>
<td></td>
</tr>
<tr>
<td>Reading</td>
<td>20 (69)</td>
</tr>
<tr>
<td>Writing</td>
<td>25 (86)</td>
</tr>
<tr>
<td>Counting</td>
<td>20 (69)</td>
</tr>
</tbody>
</table>

Behaviour problems

Carers reported a variety of behaviour problems exhibited by the PWLD. To ascertain the amount and severity of behavioural problems exhibited, descriptive analyses were conducted. The most common challenging behaviour that was reported by carers as a management problem was temper tantrums (48 per cent). Seventeen
per cent of carers viewed temper tantrums as a severe management problem. Temper 
tantrums were followed by Self-Injurious Behaviour (SIB) (45 per cent), this was 
reported as a severe management problems in 17 per cent of cases. The third most 
common behaviour problem was destructiveness (41 per cent), with 14 per cent of 
carers reporting that this caused them severe management problems. See Table 3 for 
details of other behavioural problems. As can be seen in table 3, aggression and SIB, 
which are considered serious behaviour problems, were reported as occurring in a 
third and just under a half of PWLD respectively.

Table 3

**Behaviour problems exhibited by people with learning disabilities**

<table>
<thead>
<tr>
<th>Type of problem</th>
<th>Level and severity of problem, number and (per cent)</th>
<th>Total number and (per cent)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe</td>
<td>Lesser</td>
</tr>
<tr>
<td>----------------------------</td>
<td>-------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Temper tantrums</td>
<td>5 (17)</td>
<td>9 (31)</td>
</tr>
<tr>
<td>SIB</td>
<td>8 (28)</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Destructiveness</td>
<td>4 (14)</td>
<td>8 (28)</td>
</tr>
<tr>
<td>Aggression</td>
<td>4 (14)</td>
<td>6 (21)</td>
</tr>
<tr>
<td>Screaming</td>
<td>3 (10)</td>
<td>6 (21)</td>
</tr>
<tr>
<td>Over-activity</td>
<td>2 (7)</td>
<td>4 (14)</td>
</tr>
<tr>
<td>Attention seeking</td>
<td>5 (17)</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Wandering off or running away</td>
<td>2 (7)</td>
<td>4 (14)</td>
</tr>
<tr>
<td>Difficult or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Objectionable habits</td>
<td>1 (3)</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Disturbing at night</td>
<td>1 (3)</td>
<td>4 (14)</td>
</tr>
<tr>
<td>Creates chaos</td>
<td>2 (7)</td>
<td>2 (7)</td>
</tr>
<tr>
<td>Sexual delinquency</td>
<td>3 (10)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Anti-social behaviour</td>
<td>1 (3)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

An issue related to management problems is the length of time a carer can leave the 
PWLD unsupervised in a room without having to check on them. In this sample the
majority of PWLD could be left alone for relatively long periods. Fifty-one per cent of carers reported that they could leave the PWLD alone for over two hours at a time; seven per cent were able to leave the PWLD alone for periods of between one and two hours; and 14 per cent were able to leave the PWLD for between 30 minutes and one hour. Just over a quarter (28 per cent) of carers reported being able to leave the PWLD for 15 minutes or less. However, just under half of carers (45 per cent) regarded the issue of supervision as problematic.

SERVICE AWARENESS AND RECEIPT

This section will explore the following questions:

1. To what extent are African/Caribbean carers aware of available statutory sector services for people with learning disabilities?
2. What types of statutory sector services do these families use and to what extent?
3. What factors are associated with service awareness and receipt? Specifically to what extent are carers satisfied with day and respite care services?

To discover the range of services carers were aware of, in addition to the different types of services used, descriptive analyses were carried out on data generated by the CSRI. Table 4 presents the percentage of carers who were aware of a range of services and also the percentage PWLD who were actually in receipt of the same services over the past six months.
Table 4

User receipt of services in the past six months and carer awareness of services

<table>
<thead>
<tr>
<th>Service</th>
<th>Service receipt</th>
<th>Carer awareness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Per cent</td>
</tr>
<tr>
<td><strong>Specialist:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day care</td>
<td>26</td>
<td>86</td>
</tr>
<tr>
<td>Transport</td>
<td>19</td>
<td>66</td>
</tr>
<tr>
<td>Social worker</td>
<td>16</td>
<td>55</td>
</tr>
<tr>
<td>Support worker</td>
<td>15</td>
<td>52</td>
</tr>
<tr>
<td>Respite care</td>
<td>10</td>
<td>35</td>
</tr>
<tr>
<td>Advocate</td>
<td>10</td>
<td>35</td>
</tr>
<tr>
<td>Speech therapist</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>L.D. nurse</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Physio</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Vol. Visitor</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Clin. Psych</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Additional support team</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>O.T.</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ed. Psych</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td><strong>General:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>G.P.</td>
<td>16</td>
<td>55</td>
</tr>
<tr>
<td>Dentist</td>
<td>16</td>
<td>55</td>
</tr>
<tr>
<td>Hospital out-patient</td>
<td>10</td>
<td>35</td>
</tr>
<tr>
<td>Medical consultant</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Chiropodist</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>District nurse</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Employment agency</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Optician</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Audiologist</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Nursing auxiliary</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Day patient</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>CPN</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 4 shows that awareness of all services for PWLD (general community health and social services and specialist services) generally is high, although awareness of specialist services is slightly lower in most cases. Awareness of the 13 general...
community services ranged from 69 per cent to 100 percent. Awareness of specialist services for PWLD was more variable than that of general community services, and ranged from 35 per cent to 100 per cent.

While awareness of services was generally high, service receipt was generally low and more variable than service awareness. This ranged from no one with learning disabilities using a service in the past six months (e.g., occupational therapy), through to 55 per cent and 66 per cent receiving input from social workers and transport services respectively.

**Exploratory data analysis**

To address research questions 3, 4 and 6, (i.e., what factors are associated with awareness and receipt of services? What factors are associated with carer satisfaction with services? And what factors are associated with higher levels of carer stress?) Bivariate correlations were carried out. To ascertain whether the tests should be parametric or non-parametric, a series of exploratory tests were carried out on the data. Some factors used in the analyses such as, level of disability, amount of services being received and the amount of time the PWLD could be left unsupervised, were found to be normally distributed. Other factors such as, the amount of day care received, the amount of respite care received, and the amount of behavioural problems exhibited by the PWLD, were not normally distributed. Square root transformations were conducted on those factors that were not normally distributed. However, as these transformations failed to correct the skewed
distributions adequately, both parametric and non-parametric tests were used to analyse the data. When the data were found to be normally distributed, Pearson’s correlation (r) was used to analyse the data. When the data were found to be not normally distributed Kendall’s tau (tau_b) was used in the analyses.

Factors related to carers’ awareness of services

To examine the factors associated with awareness of the available community general health and social services, a series of bivariate correlations (Pearson’s correlation was used when the data were normally distributed, and Kendall’s tau was used when the data were not normally distributed) were conducted between awareness and a range of other variables, (e.g. receipt of services, level of disability of the PWLD, behavioural problems, the amount of day care and respite care received and the length of time the PWLD could be left unsupervised).

These tests were conducted to ascertain what factors in the sample were related to service awareness. In addition, it was hoped that tentative comparisons might be made with the Azmi et al (1996) study, which the present study attempted to replicate. Table 5 shows that no significant correlations were found between awareness and the variables examined.
Table 5

Factors related to carer awareness of general and specialist services

<table>
<thead>
<tr>
<th>Factors</th>
<th>Correlation coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall amount of services received</td>
<td>r=0.100</td>
</tr>
<tr>
<td>Level of disability</td>
<td>r= -0.181</td>
</tr>
<tr>
<td>Amount and severity of behavioural problems</td>
<td>tau_b = 0.114</td>
</tr>
<tr>
<td>Amount of day care used</td>
<td>tau_b = 0.059</td>
</tr>
<tr>
<td>Amount of respite care used</td>
<td>tau_b = 0.162</td>
</tr>
<tr>
<td>Time person can be left unsupervised</td>
<td>r = 0.276</td>
</tr>
</tbody>
</table>

ns non-significant

Factors related to service receipt of adults with learning disabilities

In order to discover what factors were associated with service use in the sample, a series of bivariate correlations (Pearson’s correlation and Kendall’s tau) were carried out on the data. As Table 6 shows, two factors were associated with service receipt: the amount of day care used and the amount of respite care used.
**Table 6**  
**Characteristics of people with learning disabilities related to service receipt**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Correlation coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of disability</td>
<td>$r = 0.227$</td>
</tr>
<tr>
<td>Amount and severity of behavioural problems</td>
<td>$\tau_b = 0.159$</td>
</tr>
<tr>
<td>Amount of day care used</td>
<td>$\tau_b = -0.291^*$</td>
</tr>
<tr>
<td>Amount of respite care used</td>
<td>$\tau_b = -0.374^*$</td>
</tr>
<tr>
<td>Time person can be left unsupervised</td>
<td>$r = 0.297$</td>
</tr>
</tbody>
</table>

* $p < 0.05$

**Day Care**

In order to discover the pattern of day care service use, descriptive analyses were carried out. In this sample a very high percentage of PWLD were receiving a fair range of day services. The majority of PWLD (16 people, 55 per cent) were receiving day care in the form of Adult Training Centres (ATC). Seventeen per cent were in Further Education (FE). A very small proportion of PWLD (2 people, seven per cent) were receiving day services from more than one source, ATC and FE. However, there were four PWLD, (14 per cent) who were not in receipt of any day care services.

The amount of day care received was variable, from no day care at all, to the maximum amount of day care (five days per week). The majority of PWLD received
a full day care service (13 PWLD; 45 per cent); 17 per cent received day care on four
days per week; 14 per cent received three days of day care per week; seven per cent
received two days of day care per week, and one person (3 per cent) received one day
only per week. As previously mentioned 14 per cent of the sample was not receiving
day care of any kind.

Carers’ satisfaction with day care services

To discover how satisfied carers were with the day care services they received,
descriptive analyses were carried out. The majority of carers (93 per cent) rated the
amount of day care received as being sufficient for their needs and those of the
PWLD. Twenty-eight per cent of carers rated day care quality as “very good” and 24
per cent rated the quality of day care as “excellent”. This was despite 79 per cent of
carers reporting that there were no arrangements made by day services that were in
any way culturally specific to people from African and Caribbean backgrounds.

Carers were asked how day care services could be improved to better meet the needs
of African/Caribbean PWLD and their families. The most common improvements
reported for day care were: the employment of staff who are sensitive to the cultural
needs of users (18 carers; 62 per cent); more African/Caribbean staff working at day
services (13 carers; 45 per cent); appropriate dietary requirements (five carers; 17 per
cent); activities that are culturally relevant (4 carers; 14 per cent); provision of single
sex day care services (4 carers; 14 per cent); and “other improvements” (eight carers;
28 per cent). Table 7 presents the amount and type of day care used and carers’
ratings of their satisfaction with this service.
Table 7

Day care received by person with learning disabilities (PWLD)

<table>
<thead>
<tr>
<th>Type of day care:</th>
<th>Number</th>
<th>(Per cent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATC/SEC</td>
<td>16</td>
<td>(55)</td>
</tr>
<tr>
<td>Further Education (FE)</td>
<td>5</td>
<td>(17)</td>
</tr>
<tr>
<td>ATC and FE</td>
<td>2</td>
<td>(7)</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>(7)</td>
</tr>
<tr>
<td>No day care received</td>
<td>4</td>
<td>(14)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of days a week:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Five days</td>
<td>13</td>
<td>(45)</td>
</tr>
<tr>
<td>Four days</td>
<td>5</td>
<td>(17)</td>
</tr>
<tr>
<td>Three days</td>
<td>4</td>
<td>(14)</td>
</tr>
<tr>
<td>Two days</td>
<td>2</td>
<td>(7)</td>
</tr>
<tr>
<td>One day</td>
<td>1</td>
<td>(3)</td>
</tr>
<tr>
<td>No day care received</td>
<td>4</td>
<td>(14)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carers’ ratings of satisfaction with amount of day care received:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor</td>
<td>2</td>
<td>(7)</td>
</tr>
<tr>
<td>OK</td>
<td>3</td>
<td>(10)</td>
</tr>
<tr>
<td>Good</td>
<td>3</td>
<td>(10)</td>
</tr>
<tr>
<td>Very good</td>
<td>5</td>
<td>(17)</td>
</tr>
<tr>
<td>Excellent</td>
<td>12</td>
<td>(41)</td>
</tr>
<tr>
<td>Not applicable</td>
<td>4</td>
<td>(14)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carers’ ratings of the quality of day care:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor</td>
<td>2</td>
<td>(7)</td>
</tr>
<tr>
<td>OK</td>
<td>2</td>
<td>(7)</td>
</tr>
<tr>
<td>Good</td>
<td>6</td>
<td>(21)</td>
</tr>
<tr>
<td>Very good</td>
<td>8</td>
<td>(28)</td>
</tr>
<tr>
<td>Excellent</td>
<td>7</td>
<td>(24)</td>
</tr>
<tr>
<td>Not applicable</td>
<td>4</td>
<td>(14)</td>
</tr>
</tbody>
</table>
Respite Care

Descriptive analyses were carried out to discover the level of respite care used in the sample. The uptake of respite care services was generally lower than that of day care ones. The amount of respite care used by the PWLD varied (range: from zero stays in respite care over the previous twelve months to 24 times). PWLD had on average respite care five times a year, with a median of zero. However, respite care was not normally distributed; the majority of PWLD received little or no respite care. Nineteen PWLD (66 per cent) receive no respite care, this was despite all carers being aware that respite services were available. Three PWLD (10 per cent) had used respite services on between one and two occasions in the past twelve months. However, 14 per cent (four PWLD) had used respite services twelve times and ten per cent (3 PWLD) had used these services 24 times over the past twelve months. All respite care was provided in the form of nights away or weekends away at statutory sector accommodation. There was no provision in the form of adult family placement or domiciliary support in this sample.

The parents of the 19 PWLD who were not receiving respite services reported a range of reasons why this was the case. These ranged from carers feeling that respite services did not suit the needs of the PWLD (14 per cent), through to carers worries about abuse while PWLD were in the care of respite services, and the PWLD not wanting to go and fretting while away.
Carers' satisfaction with respite services

Descriptive analyses were conducted to discover how satisfied carers were with the respite services they received, alongside how carers believed these services could be improved. Of the ten carers whose son or daughter were receiving respite care, seven (70 per cent) reported that the amount of respite received was sufficient for their needs, and eight (80 per cent) rated the quality of respite services received as between “good” and “excellent”.

Carers' opinions were asked about how they felt services could be improved, the responses were as follows: greater awareness amongst staff on culturally appropriate ways of caring (19 carers; 66 per cent); more respite places needed (19 carers; 66 per cent); more awareness amongst African/Caribbean people about respite services (12 carers; 41 per cent); more easily accessible ways of receiving respite services (11 carers; 38 per cent); staff and users matched according to their sex (11 carers; 38 per cent); family based respite care provided within same race families (eight carers; 28 per cent); staff and users matched according to their race (five carers; 17 per cent); and “others” (four carers; 14 per cent).

CARERS' VIEWS OF OVERALL SERVICES

What are carers’ perceptions and view of the services being used? To what extent are carers satisfied with the services? What are their views about how these can be improved?
Carers' satisfaction with overall services being received

Descriptive analyses were conducted to discover the general level of carer satisfaction with the services being received. The majority of carers (sixteen carers, 55 per cent) were satisfied with the services they were receiving. Seven carers (24 per cent) reported being dissatisfied with the services they were receiving. One carer (3 per cent) reported being neither satisfied or dissatisfied with services. However, five carers (17 per cent) reported that they were not receiving enough services to be able to comment. Carers' apparent satisfaction with services was not reflected in who they reported to be their preferred choice of support and help in a crisis, or when they felt they required advice regarding the care of the PWLD. Twenty-one per cent of carers reported that they would go to services if there was a crisis, however, the majority of those who would approach services at a time of crisis would prefer to contact voluntary services as opposed to statutory specialist services for PWLD; 14 per cent reported that they would go to voluntary services and seven per cent reported they would approach statutory services in similar circumstances.

Seventy-nine per cent of carers reported that they would not approach services at a time of crisis, preferring to go to their family networks, friends and others such as the church. Thirty-eight per cent reported that they would go to services in the first instance to ask for advice or help. Fifty-five per cent reported that they would always go to their family first, and one carer (three per cent) reported that she felt she had no one to turn to for advice or help. Carers' reports regarding their disinclination to turn to services in times of crisis or trouble was reflected in their confidence in the capacity of services to help in time of crisis, with the majority of carers (59 per cent)
reporting little confidence in services.

**Factors related to carers' satisfaction with the services being received**

Bivariate correlations (Pearson's correlation and Kendall's tau) were carried out on the data to discover what factors were related to carer satisfaction. This was to establish what factors are related to satisfaction in African/Caribbean carers in the current sample. The results of these analyses are presented in Table 8, which shows a strong association between the amount of day care services received and carers’ overall satisfaction with services. The positive correlation suggests that the more day care received by the PWLD the more satisfied the carer reported being with the services received. Two additional factors showed a trend towards significance.

**Table 8**

**Factors related to carer satisfaction with services being received**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Satisfaction with services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of carer</td>
<td>$r = 0.118$</td>
</tr>
<tr>
<td>Overall amount of services being received</td>
<td>$r = 0.355$ '</td>
</tr>
<tr>
<td>Level of disability of PWLD</td>
<td>$r = 0.15$</td>
</tr>
<tr>
<td>Amount of day care used by PWLD</td>
<td>$\tau_b = 0.560$ **</td>
</tr>
<tr>
<td>Amount of respite care used by PWLD</td>
<td>$\tau_b = 0.305$ '</td>
</tr>
</tbody>
</table>

' trend towards significance  ** p<0.01
Carers' opinions about how overall services can be improved

Given that receipt of both general and specialist services for PWLD was generally low in this sample, carers were asked for their opinions about possible barriers to service uptake by carers and PWLD from African/Caribbean communities. The most common barriers to service uptake cited were: a lack of awareness of the available services (20 carers; 69 per cent); culturally inadequate and inappropriate services (12 carers; 41 per cent); discrimination in service provision (three carers; ten per cent); and "other reasons" (seven carers; 24 per cent) which included lack of trust in services, (four carers; 14 per cent); and services charges (two carers; seven per cent).

Carers' opinions on what could be done to improve access and quality of services so that more people from African/Caribbean communities would use them are as follows: more publicity about services both in the mainstream and the black media, to increase awareness about services; (18 carers; 62 per cent); support networks for families (12 carers; 41 per cent); the employment of more African/Caribbean staff in services (31 per cent); culturally sensitive services (eight carers; 28 per cent); and "others" (six carers; 21 per cent). The above information is presented in greater detail in Table 9.
Table 9

Carer's opinions about barriers to service uptake and how service uptake might be improved

<table>
<thead>
<tr>
<th>Barriers to uptake of services</th>
<th>Number</th>
<th>(Per cent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of awareness of available services</td>
<td>20</td>
<td>(69)</td>
</tr>
<tr>
<td>Culturally inappropriate services</td>
<td>5</td>
<td>(17)</td>
</tr>
<tr>
<td>Discrimination in service provision</td>
<td>4</td>
<td>(7)</td>
</tr>
<tr>
<td>Other barriers</td>
<td>2</td>
<td>(7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How access and quality might be improved</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>More publicity generally and specifically in the black media</td>
<td>18</td>
<td>(62)</td>
</tr>
<tr>
<td>Support networks</td>
<td>12</td>
<td>(31)</td>
</tr>
<tr>
<td>More African/Caribbean staff</td>
<td>9</td>
<td>(28)</td>
</tr>
<tr>
<td>Culturally sensitive services</td>
<td>8</td>
<td>(3)</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td>(3)</td>
</tr>
</tbody>
</table>

Carers' needs

To discover how far carers felt their particular needs (as opposed to the needs of their offspring) were being met by services, they were asked about what provisions were made for them as carers, what services they received, and what other services would improve their quality of life. In terms of services provided for carers, 16 carers (55 per cent) reported being a member of a carers’ support group, 11 (38 per cent)
reported receiving services from a social worker; eight (28 per cent) reported being in receipt of respite services, and four (14 per cent) reported that they received the support of “other” services. However, 28 per cent of carers reported that there was no provision made for them. In addition to the above, carers were asked to report on how far they felt their needs were being met by services. Fifteen carers (51 per cent) reported that their needs were being met to some extent; three per cent of these reported that their needs were completely met, three per cent reported that their needs were being mostly met and 45 per cent reported that their needs were being met to some extent. However, almost half of carers (49 per cent) reported that their needs were not being met at all.

In terms of the services that would be required to support them as carers, the most common response given was ‘someone to understand, advise and support them’ (15 carers, 52 per cent). Other responses were: ‘more appropriate support at home’ (four carers; 14 per cent), ‘more appropriate support in respite care’ (four carers; 14 per cent) and ‘support from other African/Caribbean carers who are in a similar position’, e.g. black carers’ support group (3 carers; ten per cent). Ten per cent of carers felt “other” services would be helpful to them in their role as carers.

STRESS LEVELS IN CARERS

This section will explore levels of stress in carers and the factors associated with stress. Stress levels were measured by means of two instruments, the Malaise Inventory (MI) and the Short-form Questionnaire of Resources and Stress (QRS-F).
A number of correlations (Pearson’s correlation and Kendall’s tau) were conducted with the stress measures to discover what factors were related to higher levels of stress. The factors entered in the analyses were those that might be intuitively related to stress, in addition to some of the factors found to be associated with stress in previous studies. For example, level of disability of the person being cared for, the number of behavioural problems exhibited by the PWLD (e.g., Tew et al., 1975; Chetwynd, 1985).

Before presenting further statistical findings, carers’ scores on the MI will be compared with those obtained in previous studies which used this measure with parents caring for someone with disabilities. Table 10 presents the mean scores and the percentage of carers scoring above the cut-off point for psychiatric distress in the present and in a number of other research studies. This was carried out to tentatively compare the level of stress reported in the current sample to stress levels reported in previous studies with parents caring for someone with disabilities. As table 10 shows, 56 per cent of African/Caribbean carers in the present study scored above the cut-off point on the MI, compared to 78 per cent of Asian carers scoring above the cut-off point in the Azmi et al (1996) study. The percentage scoring above the cut-off point in the present study was higher than that found in some previous studies with carers from the indigenous population (e.g., Sloper, Cunningham, Knussen & Turner, 1988); but lower than found in others (e.g., Sloper & Turner, 1991).
Table 10

Carers stress: Mean score and percentage above cut-off on the MI

<table>
<thead>
<tr>
<th></th>
<th>Mean score</th>
<th>Per cent above cut-off</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>African/Caribbean main carer</strong></td>
<td>6.7</td>
<td>56</td>
</tr>
<tr>
<td>(current study)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Asian parents of PWLD</strong></td>
<td>8.7</td>
<td>78</td>
</tr>
<tr>
<td>(Azmi et al 1996)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parents of children with</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>physical disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Sloper and Turner, 1991)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mothers</strong></td>
<td>7.4</td>
<td>67</td>
</tr>
<tr>
<td><strong>Fathers</strong></td>
<td>4.8</td>
<td>39</td>
</tr>
<tr>
<td><strong>Parents of young adults with</strong></td>
<td>n/a</td>
<td>64</td>
</tr>
<tr>
<td>challenging behaviour</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Kiernan and Alborz, 1994)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mothers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parents of children with Down's</strong></td>
<td>5.1</td>
<td>36</td>
</tr>
<tr>
<td>syndrome**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Sloper et al., 1988)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mothers</strong></td>
<td>3.8</td>
<td>24</td>
</tr>
<tr>
<td><strong>Fathers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parents of adolescents with</strong></td>
<td>5.0</td>
<td>32</td>
</tr>
<tr>
<td>Down's syndrome**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Sloper and Turner, 1994)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mothers</strong></td>
<td>4.2</td>
<td>39</td>
</tr>
<tr>
<td><strong>Fathers</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Factors related to carer stress

A number of correlations were performed with a view to identifying the factors associated with higher levels of carer stress (Pearson’s correlation and Kendall’s
Two sets of separate correlations, one for each of the two stress measures were conducted.

The correlations with the MI revealed that the only factor associated with stress levels was the number of health problems carers suffered from. The positive correlation shows that the more health problems experienced by the carer the higher the reported level of stress. Table 11 presents the results of these tests.

**Table 11**

**Factors related to levels of carer stress as measured by the MI**

<table>
<thead>
<tr>
<th>Factors</th>
<th>Stress – Malaise Inventory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of carer</td>
<td>r= 0.139</td>
</tr>
<tr>
<td>Overall amount of services being received</td>
<td>r= 0.057</td>
</tr>
<tr>
<td>Carers’ overall satisfaction with services being received</td>
<td>r= -0.262</td>
</tr>
<tr>
<td>Level of disability</td>
<td>r= -0.175</td>
</tr>
<tr>
<td>Amount and severity of Behavioural problems</td>
<td>tau _b = 0.097</td>
</tr>
<tr>
<td>Amount of day care used</td>
<td>tau _b = -0.56</td>
</tr>
<tr>
<td>Amount of respite care used</td>
<td>tau _b = 0.205</td>
</tr>
<tr>
<td>Time person can be left unsupervised</td>
<td>r= -0.237</td>
</tr>
<tr>
<td>Number of health problems the carer suffers from</td>
<td>r= 0.809 **</td>
</tr>
</tbody>
</table>

**p<0.01

A number of t-tests were carried out to discover whether factors such as marital status, financial hardship and housing inadequacy impacted upon the stress levels of carers, as measured by the Malaise Inventory (MI). The factors chosen were those that had been shown to be related to higher levels of carers stress in previous studies (e.g., Beckman, 1983; Grant et al, 1990). Previous research has shown that factors such as employment status and level of household income can be related to higher
stress levels in carers (e.g., Grant et al., 1990). However, there was little variability in the data obtained on household income and employment status in the current sample.

There were no differences in stress levels between married and non married participants, between those experiencing financial difficulty and those who were not, and between those who felt their accommodation was adequate and those who did not. Additional measures of material deprivation, (e.g., income and level of unemployment), could not be used in these analyses due to a very high percentage of the sample falling into the lowest income bracket and being unemployed. In other words, the sample was too skewed for any meaningful comparisons to be made. The results of these t-tests are presented in Table 12.

Table 12

Mean differences in marital status, financial difficulty, housing adequacy and carers stress level as measured by the MI

<table>
<thead>
<tr>
<th>Factors</th>
<th>Malaise Inventory</th>
<th>t(27)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>5.40 (4.81)</td>
<td>7.37 (4.74)</td>
<td>-1.058 ns</td>
</tr>
<tr>
<td>Financial difficulty/ Difficulty meeting bills</td>
<td>5.70 (4.60)</td>
<td>7.21 (4.91)</td>
</tr>
<tr>
<td>Adequate accommodation</td>
<td>7.62 (5.12)</td>
<td>5.54 (4.22)</td>
</tr>
</tbody>
</table>

ns = non-significant

The same bivariate correlations as the ones conducted with the MI were performed
with the QRS-F. A significant correlation was found between stress and: 1) the level of disability of the person with learning disabilities, 2) the length of time the PWLD could be left unsupervised, 3) the number of health problems suffered by the carer and 4) the number and severity of behavioural problems exhibited by the PWLD. Specifically, the more disabled the person being cared for, the higher the stress levels experienced by the carer. The shorter the length of time the PWLD could be left unsupervised, the higher the stress levels of the carer. The greater the number of health problems experienced by the carer, the higher his/her stress levels. Finally, the more behavioural problems exhibited by the PWLD, the higher the stress levels experienced by the carer. Table 13 presents the factors associated with stress levels as measured by the QRS-F.

**Table 13**

**Factors related to carer stress (related to looking after someone with disabilities) as measured by the QRS-SF**

<table>
<thead>
<tr>
<th>Factors</th>
<th>Stress – QRS-F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of carer</td>
<td>$r = 0.44$</td>
</tr>
<tr>
<td>Overall amount of services being received</td>
<td>$r = -0.124$</td>
</tr>
<tr>
<td>Carers’ overall satisfaction with services being received</td>
<td>$r = 0.355$</td>
</tr>
<tr>
<td>Level of disability</td>
<td>$r = -0.623^{**}$</td>
</tr>
<tr>
<td>Amount and severity of Behavioural problems of</td>
<td>$\text{tau}_b = -0.348^*$</td>
</tr>
<tr>
<td>Amount of day care used</td>
<td>$\text{tau}_b = -0.055$</td>
</tr>
<tr>
<td>Amount of respite care used</td>
<td>$\text{tau}_b = 0.188$</td>
</tr>
<tr>
<td>Time PWLD can be left unsupervised</td>
<td>$r = -0.608^{**}$</td>
</tr>
<tr>
<td>Number of health problems the carer suffers from</td>
<td>$r = 0.515^{**}$</td>
</tr>
</tbody>
</table>

*p<0.05 **p<0.01
A number of t-tests were carried out to investigate whether factors such as marital status, financial hardship and housing inadequacy impacted upon the stress levels of carers as measured by the QRS-F. These tests were conducted to discover the effect of factors, which according to the literature, impact on carer stress levels.

As the with the MI, there was no difference in stress levels between married and non-mARRIED participants, between those experiencing financial difficulty and those who were not and between those who felt their accommodation was adequate for the family's needs and those who did not. The results of these t-tests are presented in Table 14.

Table 14
*Mean differences in marital status, financial difficulty, housing adequacy and carers stress level as measured by QRS-SF*

<table>
<thead>
<tr>
<th>Factors</th>
<th>Mean scores (SD)</th>
<th>t-values (df)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25.0 (8.26)</td>
<td>0.197 (27)</td>
</tr>
<tr>
<td>No</td>
<td>30.32 (9.45)</td>
<td></td>
</tr>
<tr>
<td>Financial difficulty and/or difficulty meeting bills</td>
<td>Yes</td>
<td>22.90 (9.15)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>21.41 (9.42)</td>
</tr>
<tr>
<td>Adequate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>19.56 (9.99)</td>
<td>-1.581 (27)</td>
</tr>
<tr>
<td>Accommodation</td>
<td>No</td>
<td>24.85 (7.45)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ns = non-significant</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SUMMARY OF MAIN FINDINGS

African/Caribbean families looking after an adult with learning disabilities in the home setting appear to be living in circumstances of material disadvantage. Sixty-six per cent had a household yearly income of less than £10,000; and unemployment was high, with 89 per cent of carers not working. Most families were relying on benefits as their main source of income and a high percentage reported experiencing financial difficulties, including difficulty with paying bills.

Many carers were looking after an adult with high support needs, in terms of the level of their offspring’s physical dependency. In addition, over a third of those being cared for exhibited serious challenging behaviours (i.e., aggression towards others and self-injurious behaviour). Most carers were coping with these difficulties on their own as 65 per cent of the sample consisted of lone parent families. However, 79 per cent felt they had the support of family or friends in times of stress or crisis.

There was a high level of service awareness in the sample of both general and specialist services, however receipt of services, with the exception of day care services, were comparatively low. As previously noted, high levels of day care services were used, with most people receiving three days or more. There was a much lower uptake rate of respite care and the majority of families (66 per cent) had not used this service over the previous 12 months.

The majority of carers were overall satisfied with the quantity and quality of the services they were receiving. Carers’ opinions about the barriers to service uptake show that most felt that a lack of awareness, alongside the cultural inappropriateness
of services, were the main barriers to service uptake. Although lack of awareness was the main reason given for low service use, the majority of carers reported little confidence in services' ability to help, with 79 per cent of carers reporting that they would not approach services in times of crisis.

Over half of the sample reported stress levels indicative of psychiatric distress, as measured by the Malaise Inventory. This is a higher rate than that observed in some studies with carers from the indigenous population (e.g. Sloper et al, 1988; Sloper et al, 1994) and lower than that found in others (e.g. Sloper et al, 1991; Kiernan et al, 1994). The percentage of carers that scored above the cut-off point on the MI was found to be much lower than that observed by Azmi et al (1996) among Asian carers.

Stress levels as measured by the QRS-F were associated with four factors: the level of disability of the person being cared for, the length of time this person could be left unsupervised, the number of behavioural problems being exhibited by the person being cared for, and the number of health problems suffered by the carer.
Chapter Four

DISCUSSION

The study aimed to identify a sample of African/Caribbean families caring for a learning disabled adult offspring in the home setting and to explore their family circumstances and characteristics. It also aimed to ascertain the type and level of services used and to explore carers' experiences of and views about services. Finally, the study also examined levels of carer stress and the factors associated with stress.

This study supports previous research findings that families from minority ethnic groups caring for an adult with learning disabilities are living in situations of material disadvantage when compared to the general population (Beresford, 1995; Azmi et al, 1996). The sample was found to have unemployment rates higher than the national average and household incomes lower than the national average (Beresford, 1995; Bridgewood & Savage, 1993). Many families were living on benefits and a large proportion were either unemployed or of retirement age and many reported financial difficulties.

Many carers were looking after a person with high levels of dependency, as well as with behavioural problems. There were a high percentage of lone parents in the sample and most had the main responsibility for their offspring’s care. Over half of the sample was found to be experiencing levels of stress that could put them at risk of developing psychiatric problems, suggesting that these families have high support
needs. Although there was a high level of awareness, service receipt was comparatively low. This suggests that many families had little support from services. Carers did, however, appear to feel they received support from family and friends at times of stress and during crises.

The majority of people with learning disabilities received a range of day care services and many received a full five-day service. The level of respite care received was much lower; two thirds of people with learning disabilities received no respite care. Overall, carers reported being satisfied with the services they received and with the amount and quality of services used. They did, however, express a lack of confidence in the capability of services to assist them in times of crisis, preferring to approach family or friends for support and assistance.

The majority of carers reported that services did not cater for their cultural needs, this was particularly true of respite care services. Carers’ opinions about methods to improve services reflected this perceived lack of cultural sensitivity. However, the main barrier to accessing services was believed to be a lack of awareness within African/Caribbean communities.

**Service awareness and receipt**

**Service awareness**

Studies exploring service awareness among black and minority ethnic communities have generally found a low level of awareness within these communities (e.g.
Ahmad et al 1996; Azmi et al, 1996; Baxter et al, 1990; CVS, 1998). The results of the present study differ from those obtained in previous research in this area, as a high level of awareness about both general and statutory services was observed.

The study by Azmi et al (1996) discussed in the introduction reported that a range of factors was related to awareness within the Asian community investigated. However, in this study no factors were found to be associated with carers' level of service awareness. It would have been interesting to explore whether the variables found to be predictive of carer awareness in the Asian sample studied by Azmi et al, (1996), could also predict awareness in the present study. However, it was not possible to examine the same factors in the present investigation. This was because there was so little variability within these factors and the distribution was very skewed. In addition, some factors simply did not apply to the present sample. For example, Azmi et al (1996) found that carers who had lived in the UK longer, had higher incomes and could speak and write English were more likely to be aware of services. In the present study the income levels were too skewed, with the vast majority of families falling into the lowest income bracket. Eighty per cent of African/Caribbean carers had lived in the UK for 20 years or longer. Moreover, there was no language barrier between services and carers in the present sample.

There may be a number of reasons for the difference between the service awareness observed in the present sample and that found in previous research. First, although awareness in the sample was high, this may or may not reflect genuine levels of awareness among African/Caribbean families caring for an adult with learning disabilities. It is possible that the results obtained are specific to the sub-group
studied, due to the methods used to obtain this sample. The sample was drawn entirely from carers who were known to services and therefore it is not surprising they were aware of services.

Previous studies, such as the Azmi et al (1996), used a total population sample to identify and recruit participants. This was facilitated by the fact that Asian communities prefer to use Asian GPs (Shah, 1995), and Azmi et al (1996) reported using this source to identify and recruit families who had no contact with specialist services. The sample used in the present study was therefore dissimilar to those used in previous studies by virtue of being a highly selected group.

It is interesting that this group of carers although themselves very aware of services, believed that African/Caribbean people generally have a lack of awareness of the available services. A number of carers mentioned the inability of services to effectively disseminate information about what they do and how to access them. One carer who looks after two adult offspring with learning disabilities commented “I haven’t always known about what I was entitled to. For years I was struggling on my own to cope with two disabled children. Many a time I found out how I could get help from other parents. Sometimes even other black people (strangers) on the street have stopped me to ask if I get help with my daughter, and told me about some other service I didn’t know about”.

Service receipt

In contrast to the relatively high levels of carer awareness, receipt of all services with
the exception of day care, was generally low. This picture of poor service uptake is consistent with previous research findings and recent literature in this area (e.g. Ahmad & Atkin, 1996; CVS report 1998, Kernan & Walker, 1981; Nadirshaw 1997). The results of the present study suggest that African/Caribbean families caring for an adult with learning disabilities experience difficulties with accessing services, despite being aware of them. The minority of families who used respite services, received these in the form of nights or weekends away in statutory sector buildings. None received the more innovative schemes (e.g., adult placement within families), despite these being available in at least one of the boroughs from which participants were drawn.

Respite care is an important service for supporting families and is regarded as an integral part of community care. It has been described as having among its purposes the prevention or delay of out of home placement (e.g., Stalker & Robinson, 1994). It is of some concern that the majority of African/Caribbean families were found not to be in receipt of this vital service, given that high numbers were single-handedly caring for someone with high support needs. In addition, over half of those interviewed were experiencing levels of stress indicative of psychiatric distress.

Azmi et al (1996) found that use of respite care services in Asian families was low, when compared to white families in a similar situation. Although the level of respite care received in this sample was higher than in the Asian sample, this was nonetheless lower than that reported in previous research of white families in similar circumstances. For example, Evans et al (1994) found that 47 per cent of families in their study used respite care services. Therefore, in line with previous research
findings, uptake rates of respite services appear to be lower in minority ethnic communities than those reported in studies using the indigenous population (e.g. Azmi et al, 1996; Evans et al, 1994).

In this sample, the use of specialist services during the six months prior to the investigation tended to be higher than the use of general and welfare services, which contrasts with previous research (e.g. Azmi et al, 1996; CVS report, 1998). Despite service receipt being overall lower than service awareness, receipt was relatively high, for some services, e.g. social worker and support worker (over 50 per cent), although, this was observed only in relation to a few services. Generally, service receipt in the African/Caribbean families in this sample was lower than that reported in research using families in similar situations from the indigenous population (e.g. Beresford, 1995; Evans et al, 1994).

In this study a high proportion (55 per cent) of African/Caribbean carers were members of carer support groups. This service has been highlighted in the literature as a valued source of support for people caring for a person with learning disabilities in the home setting. This finding is not in line with previous studies, which indicate that people from minority ethnic communities are less likely than their white peers to use this service (Azmi et al, 1996; Beresford, 1995). Although this finding is unusual, it is perhaps accounted for by the fact that a number of carers were recruited from a carers’ support group.
Satisfaction with services

Many of the carers in this sample were looking after a person with a high level of support needs. Generally, with the exception of day care services, they were not in receipt of many specialist services. Although the majority (55 per cent) reported being to some extent overall satisfied with the services they were receiving, it is important to bear in mind that a large proportion (45 per cent) reported dissatisfaction with the services used. This may however, be even higher, as it is possible that carers felt reluctant to evaluate services negatively, or were wary of complaining because they were fearful of losing services. As one carer commented “A lot of these people (black carers) don’t like to complain, they seem to think that they should be grateful for whatever little they get and are afraid of it being taken away, as if they are not entitled to it in the first place”.

Carers were generally more satisfied with the amount and quality of day care services being received than they were with respite services. However, the majority of people with learning disabilities (86 per cent) were using day care services in comparison to only 35 per cent using respite services. The amount of day care being received was positively correlated with the level of carer satisfaction. In other words, the greater the amount of day care received by the person with learning disabilities, the more satisfied his or her carer was overall with the services being received.

The percentage of African/Caribbean carers in the present sample reporting satisfaction with services was higher than observed among Asian carers (Azmi et al, 1996). However, it was lower than that found in previous research with carers from
the indigenous population. Thus, this finding is consistent with previous research suggesting that satisfaction with services may be lower in families from minority ethnic communities than in the indigenous population (e.g. Beresford, 1995). General satisfaction with day care services among carers was moderately high, despite the majority of carers (79 per cent) reporting that there were no culturally specific arrangements made for their son or daughter. This was surprising, because most carers (62 per cent) thought that the employment of staff members that are sensitive to cultural needs would potentially improve day care services. The majority of carers (66 per cent) also reported that greater awareness among staff on culturally appropriate ways of caring would improve respite care.

Many carers expressed exasperation with staff members’ inability or unwillingness to grasp what they felt were very simple and basic personal care needs for African/Caribbean people. This was generally related to black hair and skin care. This will be illustrated by two of the many comments made by carers to the researcher. One carer reported “every time (name of son) goes to (name of respite home) I send him with a bag with his cream (moisturising lotion). I can’t tell you the number of times I have told staff down there that he needs to cream his skin whenever he has a bath. Each time he comes back with the bag the same way it hasn’t been touched. Either they can’t understand or don’t care, its too much work and they can’t be bothered”. Another reported “when (name of daughter) goes there they don’t comb her hair, she either comes home one day for me to plait her hair or she comes back looking a state”.

The percentage of carers reporting that their needs as carers were being met was very
similar to the figures for overall satisfaction with services. Fifty-two per cent reported that their needs were being met to some extent by services. However, almost half of the sample felt their needs were not being met at all and some felt these were being overlooked by services. In response to the question “to what extent do you feel your needs as a carer are being met?” one carer responded, “not at all, services are not there for me as a parent, they are not interested in what is going on in my life, whether I am struggling or not. The only time they seem to be bothered about me is when (name of son) has a review coming up or if there is some problem with (name of son) down at (name of a day centre), otherwise I am just left to get on with it the best I can”.

Despite more than half the sample reporting overall satisfaction with services and that their needs were being met, this satisfaction was not reflected in the level of confidence in the capacity of services to help at times of crisis. Only 21 per cent reported that they would approach services in times of crisis, with 79 per cent preferring to go to family and friends. Possible explanations for preferring to seek help from informal networks (e.g., family, friends, the church) might be, African/Caribbean carers have previously found that help is more readily available from informal networks than from services, or some carers might not feel comfortable about taking their problems to services. They may feel that they are responsible for their child and believe that they should be able to sort things out themselves. Alternatively this preference for informal networks may be explained by carers lack of trust in services to be able to help them in meaningful ways. A number of carers commented that they felt services were not very helpful or could not respond rapidly enough to be useful at a time of crisis.
In relation to carers’ opinions about how to improve their quality of life, over half of the sample reported wanting someone to understand, advise and support them. Many believed that this would be most beneficial if support was given by someone who was connected to services in some way, and therefore could act as a liaison person between carers and services. However, most commented that this person needed to understand the position of black carers, and people with learning disabilities. For a number of years, theorists in the area of service provision to black and minority ethnic communities have highlighted the need for more black advocates. This measure would fulfil the function described by many carers in this sample (e.g. Atkin et al, 1996; Baxter et al, 1990; Kernan et al, 1981; Nadirshaw, 1997).

**Barriers to access and how services might be improved**

Carers’ opinions regarding barriers to service uptake and ways to improve access for African/Caribbean people with learning disabilities and their families were consistent with the literature and previous research (Ahmad et al, 1996; Azmi et al, 1996; Baxter et al, 1990; CVS 1998; Nadirshaw, 1997). The majority of carers felt that, in general, African/Caribbeans are not as aware of the available services as they should be. In addition, carers believed that, if more information were given about the available services, access and quality would be improved. This was an interesting finding, considering the high level of awareness amongst the sample studied. This may indicate that the sample might not be completely representative of people from African/Caribbean communities. Alternatively it might indicate the possibility that some African/Caribbean carers are indeed more aware of the available services than
previously thought.

The provision of culturally sensitive services was one of the most frequently mentioned of the potential improvements to services. This is in accordance with most of the previous research in this area (e.g. Azmi et al, 1996; Baxter et al 1990; Nadirshaw, 1997). Within the sample studied, cultural sensitivity appeared to be related to black identity, as well as cultural needs. For example, a number of carers commented that their son or daughter seemed to feel ashamed to be black. It was believed that this was due to the lack of positive images of black people being portrayed in society generally and within the services. This was despite the efforts of some carers who tried to reinforce in their son or daughter, a positive image of black people and black culture. One mother commented that her son did not want to be African and black because ‘black is bad’. She felt that because people with learning disabilities spend the majority of their time in day centres, these services in particular, should promote a more positive image of black people and their cultures by having more activities and materials reinforcing positive images of black people. For example, books, posters and materials depicting black images. This reflects some of the suggestions which have been made in the literature (e.g., Baxter et al, 1990; Nadirshaw, 1997).

Carers who participated in this study were of the opinion that services are either unaware of basic requirements that African/Caribbeans have or are not willing to translate knowledge into practice. Other improvements suggested by carers also reflect concerns that have been raised in the literature over recent years, e.g. the lack of black and minority ethnic staff in services. This aforementioned measure to
improve access and quality of services was reported by just under a third of carers.

Some carers also felt that if more activities such as, African/Caribbean cookery and music etc, were provided in day services, their son or daughter might feel more comfortable and less isolated within the services they use.

**Carer stress**

In the current study two measures were used to ascertain the level of carer stress and explore the factors associated with this. Over half (56 per cent) of the sample reported stress levels indicative of psychiatric distress. These stress levels are higher than those observed in some studies (e.g. Sloper et al, 1998; Sloper et al, 1994) but lower than those observed in others (e.g. Azmi et al, 1996; Kiernan et al, 1994; Sloper et al, 1991). Although the levels of stress in the present study were higher than recently found in other minority ethnic carers (e.g. Azmi et al, 1996), they are nonetheless a cause for concern. Particularly when accompanied by low service uptake, coupled with carers receiving relatively few services and having the main responsibility for someone with high levels of need. The low uptake rate of respite services in the context of the high stress levels observed among carers is also a cause for concern. One factor only was found to be associated with stress as measured by the Malaise Inventory, this being the number of health problems suffered by the carer. This indicates that the more health problems being experienced, the higher the stress level of carers.

The fact that stress levels in this sample were not as high as in the Azmi et al study,
(1996) might be related to the level of informal support carers perceived to be available to them in the present sample. Seventy-nine per cent felt they could turn to family and friends at times of trouble, which is a much higher level of support than found among Asian carers. It has been reported that informal and formal support can act as buffers against stress (Dunst et al, 1986). Therefore, it is possible that their perceived level of informal support did indeed act as a buffer against stress for these carers. It is also possible that the coping strategies used by African/Caribbean carers also acted as a buffer. However, as neither social support nor coping strategies was investigated by means of structured measures, no definite claims about their relationship can be made.

It is also possible that carers’ religious beliefs influenced their stress levels. A number of studies have suggested that for black people, religion and the church, functions as a major source of support and comfort (e.g., Baxter et al, 1990; Marion, 1980; Rogers-Dulan, 1995). Although a number of carers commented that they prayed when things become difficult and believed that their faith helped them to cope with difficulties, because religion was not investigated in this study it is only possible to speculate about its influence on stress levels.

Many factors have been found to be associated with stress levels in the literature and previous research. These include marital status (Beckman, 1983), low income and financial difficulties (Bradford et al, 1978; Grant et al, 1990), and high levels of physical dependency and behavioural problems (Chetwynd, 1985; Tew et al, 1975). In this study, carer stress levels as measured by the QRS-F were found to be associated with some of the above factors but not with others. It was found that
parents caring for someone with a greater level of disability, more challenging behaviours and who could not be left unsupervised for long periods, were experiencing higher stress levels. Moreover, the number of health problems a carer suffered from was associated with higher stress levels.

There were more factors associated with higher stress levels as measured by the QRS-F than found when the MI was used. This might be explained by the fact that the QRS-F measures stress related to the role of caring for someone with disabilities and the MI measures stress in terms of emotional and psychosomatic symptoms. The three factors that were associated with higher stress levels measured by the QRS-F but not by the MI, were directly related to the demands of caring for someone with disabilities. For example, caring for someone with a greater level of disability and more challenging behaviour that required a higher level of supervision, which would not necessarily be detected by the MI.

Factors such as marital status and financial difficulty were not found to be associated with stress. Indicators of material deprivation such as, level of income and employment status could not be used due to the majority of carers being on low incomes (66 per cent on less than £200 per week) and not working. Had more complex methods of measuring financial hardship been utilised, these factors may have been found to be associated with stress levels.

Beresford (1995) identified a number of groups that were reported to be particularly vulnerable to experiencing stress; these included lone parents and parents caring for offspring with greater support needs. Many families in the present study fell into the
groups mentioned by Beresford (1995). This, coupled with the levels of stress indicative of psychiatric distress observed in this sample and the poor use of respite services, suggests that this group of carers may have complex support needs. However, the low uptake rate of services indicates that these families are coping on their own in very difficult circumstances and may be at risk of breakdown. Beresford, (1995) found that services were less likely to meet the needs of families from minority ethnic communities than families from the indigenous population in similar circumstances. Given the above, it is very important that services are made more accessible to this group of carers.

LIMITATIONS OF THE STUDY

It is likely that the sample was biased by recruiting participants from only statutory or voluntary sector organisations, which increased the likelihood of carers being more aware of the available services. The researcher attempted to obtain a more representative sample by contacting various black community organisations serving people with disabilities, such as black carers associations. However, these sources were either unwilling or unable to assist, due to heavy workloads or not having any members with learning disabilities.

The bias in the sample has implications for the representativeness of the results obtained in the study; in addition to the generalisability of the research findings. The sample would have been more representative had it been extracted from a total population sample (e.g. Azmi et al, 1996). This could have been achieved by interviewing all African/Caribbean parents caring for an adult with learning
disabilities in one area, or interviewing a random sample from a much larger region (for example as obtained by Beresford, 1995).

In order to recruit as many black carers as possible, it may have been profitable to utilise adverts and to contact a wide variety of black community organisations. It is likely that a larger number of potential participants would be reached if adverts were placed in the black media. The literature suggests that many people within African/Caribbean communities are religious and have high levels of church attendance (e.g., Baxter et al, 1990). Therefore, it might have been profitable to contact black churches and church organisations. These strategies would have increased the possibility of contacting people who are not known to services. Placing adverts in GP surgeries in areas with large black communities may also have increased the likelihood of identifying people not known to specialist services. In addition, contacting organisations in the black community not specifically catering for the needs of disabled people may have identified potential participants not known to services. This would have increased the likelihood that the sample would be more representative of the target population. Although it would have been possible to employ some of the methods mentioned above, many were beyond the scope of the investigation due to time and resource constraints.

Clearly one of the major limitations of this study is the small sample size. Given the limited sample size, the current study would only have power to detect substantial effects. Consequently, one interpretation for the lack of positive findings in this study could be its inadequate power. However, the research by Azmi et al (1996) does suggest quite substantial associations between service awareness, service receipt and
various carer factors (e.g., length of residence in the UK, higher household income); with multiple R squared ranging between 0.33 and 0.53 in three multiple regressions.

It is notable that despite the small sample size of this study, 29 subjects would nevertheless have 80% power to detect an R squared of 0.33 (p<0.05), which was one of the smallest effects found by Azmi et al (1996). It seems likely then, that if there are associations between service awareness, service receipt and for example, higher household income and greater length of time carers have lived in the UK, these are not of the magnitude suggested by Azmi et al (1996). There may be several potential reasons for this apparent discrepancy. The Azmi et al (1996) study may have overestimated the effect size in particular, the use of stepwise regressions may have capitalised on chance associations. This is likely, because the researchers used only variables with strong univariate correlations (e.g., p<0.01) as independent predictors in their multiple regressions.

The other important potential explanation that deserves consideration is that this sample and the one from the Azmi et al (1996) study are in some respects very different. A number of differences have already been noted, that is: more African/Caribbean carers have lived in the UK for extended periods (over 20 years); also, English was the first language for all African/Caribbean carers, whereas many of the Asian carers had language difficulties. This was due to English being the second language for many Asians and some spoke no English at all.

There may be other differences between the Asian and African/Caribbean samples. There may have been a real difference in socio-demographic characteristics between
the two groups. The difference in ethnicity and religion may have had an influence on the results of the two studies. It is possible that other cultural and/or religious differences accounted for the differences observed within the two samples. For example, it has been documented in the literature that black and minority ethnic families can have a lack of understanding of the nature of learning disabilities and this can affect their service awareness and utilisation. However, much of the research and literature regarding this area of investigation have drawn their samples from various Asian communities (e.g., Channabasavanna et al 1885; Ellahi et al, 1992; Fatimilehin et al, 1994, Shah, 1995). Therefore, it is possible that the “lack of understanding” theory applies more to Asian communities than it does to African/Caribbean ones. This is an area that warrants further study and would benefit from making comparisons within and between the two groups rather than using Asian samples and then extrapolating to other black and minority ethnic groups.

Given the aforementioned discussion regarding the different findings obtained with the two samples, and that the current study failed to find the associations found by the Azmi et al’s (1996) study, it is likely that the effect sizes are smaller than those suggested by Azmi et al (1996). Alternatively, the two samples differed in very substantial ways, suggesting that they were investigating very different populations. Future research on populations of this kind (black and ethnic minority communities) will need to be of a larger scale and may need to consider the different meanings ascribed to learning disabilities in different groups. As already mentioned, a lack of understanding may result in low service awareness.

Another difficulty is the low response rate (42 per cent) in the current study. It is
possible that there was a difference in the level of service awareness between those carers that did and those who did not respond. In addition, the sample was invited to participate in the study in two different ways. They were either contacted directly by the researcher, or by organisations. This difference in recruitment methods impacted on the response rate. In the borough in which all potential participants were not contacted directly, only five per cent responded and subsequently took part. In boroughs in which the researcher was able to contact prospective participants directly only eight per cent of carers refused to participate.

It is possible that those carers who did not participate were less aware of the available services or more disillusioned by their experience of using services, hence their reluctance to take part. Perhaps those who refused to take part were experiencing more problems in their caring role and felt that the study would cause additional difficulties. One person who refused to participate commented: “I have struggled with my son for so many years with no help from... (Name of local community team), why should I help them and you. I am under a lot of pressure looking after my son on my own, I am on my own now and do not want any extra stress”.

The majority of carers fell into a low-income bracket, gaining their income mainly from benefits. Therefore, the study is unlikely to have reached African/Caribbean carers across the range of socio-economic categories. It is possible that a different pattern of results may have been observed had African/Caribbean carers across the range of socio-economic categories been included in the study.
There was a gender imbalance in the sample, all but one of the participants being female. It could be argued that the male participant should have been excluded, as his experiences and therefore his responses, may have been qualitatively different from those of the female carers. However, it was felt that there were probably other variables related to being an African/Caribbean carer looking after a person with learning disabilities that were more salient than gender and that made the experiences with services similar for both males and females. In addition, many of the main carers in African/Caribbean communities tend to be female (Bhalla & Blakemore, 1981: Farrah, 1986). It has been documented that many African/Caribbean families are lone parent families headed by a single female. Thus, it is not unreasonable to assume that the make up of carers of people with learning disabilities is similar to the African/Caribbean population in general (Farrah, 1986).

Although thirty-five per cent of the sample was married, the interviews were conducted with the main carer. Thus, it could be argued that the results might reflect the views of one member of the family only, and that other members might have produced different opinions. Although efforts were made to include partners, they tended to be unable to make the times suggested (and opted to allow the interview to go ahead with only one parent), or declined to take part.

The study focused on the opinions of carers and neglected the actual service users. There is the danger that the experiences, views and opinions of African/Caribbean people with learning disabilities were overlooked, as carers’ views and opinions do not always reflect those of the actual service user. Concentrating solely on carers may have resulted in the lost of some very valuable information. Had there been
more time and resources available it would have been informative and useful to explore the experiences of the service users.

The questionnaire asked carers whom they would turn to in times of crisis and whom they would go to for advice in the first instance if they needed help. This was intended to reflect individuals’ preferred source of support in times of crisis. However, it is very likely that these questions are inadequate for the task of investigating informal/social support networks, which should have been measured by the use of a standardised instrument (e.g., the Social Support Questionnaire – Revised).

There were potential difficulties with the measures used in this study. With the exception of the QRS-F, the measures were very similar to those used in the Azmi et al (1996) study. The questionnaire about the use of day care and respite care used in this study was devised and used by Azmi et al (1996). It was designed for use with Asian communities and to the researcher’s knowledge, has only been previously used by the developers. Hence, there are no data on the reliability and validity of this measure. Therefore, the validity of the questionnaire when applied to different minority ethnic communities (i.e. African/Caribbeans) is unknown. In order to establish the reliability and validity of this measure replication studies should be conducted. As already noted some of the questionnaire items about the use of day care and respite care intended to reflect concepts such as social support. However, the items were not robust enough to do so, as only one or two questions for each concept were included.
The CSRI is a checklist that has not been used extensively in psychological research. It has been used mainly as a measure to cost the use of health services. It has not been subjected to analyses to determine its reliability and validity and studies need to be conducted to establish these.

Despite many of the measures used being standardised instruments that have been utilised in many research studies, they have been used mainly with the indigenous population. To the researcher's knowledge, there are no studies that have examined the reliability of these measures with African/Caribbean and other minority ethnic groups. Therefore, more studies need to be conducted using these measures with minority ethnic groups to establish their reliability with these populations.

A major limitation of the current study was the lack of a comparison group. To be able to draw conclusions about differences between groups (e.g., Black, White and Asian) it is necessary to use the different groups in the same study. It would then be possible to extrapolate about differences in service use and opinions about services across different groups. Due to this limitation, it is not possible to make conclusive statements about which group is more aware of, and uses more of particular types of services.

The absence of a comparison group makes it difficult to say what factors are more salient to different groups, even within the domain of cultural appropriateness and sensitivity, which was of major concern to the sample studied. Although the concerns raised intuitively seem to be related to race and culture, without a comparison group it is difficult to separate out what is a complaint or problem that
would be made or perceived by anyone using services (i.e., service related) and which complaints or problems are specifically related to issues of race and culture.

Despite the aforementioned limitations, it was felt that it would be valuable and informative to conduct this investigation, due to the importance of carrying out research with a community which has been viewed as lacking trust in services (e.g. Fatimilehin et al, 1998); and often to have a sense of “being used” by researchers. This was highlighted in the researchers’ experience during the course of the study. For example, one voluntary organisation staff member refused to assist in the research due to what he called “the common practice of research using the black community by constantly taking and never giving anything in return”. The comment of a mother of two autistic adults further elucidates this point: “we have taken part in so many studies and given so much information in the hope that things will get better. All that seems to happen is people talk and have good intentions but nothing ever comes of it, yet we are still expected to be happy about providing people with information”.

Some carers do feel that they have been the subject of much research. This is contrary to what has been suggested in the literature on learning disabilities and minority ethnic communities. However, in the case of the aforementioned mother, being the mother of autistic twins has meant that the family has been the subject of much research interest and has been involved in many studies. Therefore, perhaps this carer has been involved in more research studies than other African/Caribbean carers with learning disabled offspring.
In an attempt to ‘give something back’ to the participants, summary reports will be written and sent to all participating carers. It is hoped that carers will feel that it was worthwhile participating in the current study and will not have a sense that they have been used. Summary reports will also be sent to all services that participated in the study.

Although many limitations have been highlighted, it is important to bear in mind that this was an exploratory study, which aimed to begin the process of investigating the service needs and experiences of a group that has generally been overlooked by researchers. In addition, a substantial portion of what was discovered about the present sample, was consistent with the issues highlighted in the literature as regards the experience of black and minority ethnic communities. Therefore, although caution must be exercised when extrapolating from the present study to the experience and views of African/Caribbean communities generally, it would be unwise to dismiss the results obtained from this study.

FURTHER RESEARCH

As the study employed a small number of participants, the results may not be as representative as they could be. In addition, it would be interesting to study samples that are not in receipt of any services, to investigate what their needs are and ideally, why they are not using the available services. This type of investigation should be carried out with larger numbers, possibly a total population sample of a particular area. This could be achieved by using existing registers in addition to contacting voluntary and community organisations, including churches that serve
African/Caribbean communities.

Carrying out this type of study in one area and including as many African/Caribbean families from that area as possible, could generate useful information about the support needs of part of this community and inform service planning in the medium to long term. To be able to provide appropriate services for all parts of the community that they serve, service planners need to be aware of the make up of that community. The growth and development of registers for people with learning disabilities is an important step in elucidating the prevalence of African/Caribbean people with learning disabilities. It is very important that the prevalence and incidence of African/Caribbean people with learning disabilities is known, if not nationally, at least locally, so that services are aware of the numbers and needs of all of their local community.

This study focused on African/Caribbean carers looking after a person with learning disability. As previously stated, to be able to draw conclusions about differences between groups, the groups of interest need to be examined in the same study. Therefore it would be very informative and add to the body of literature on differences in service use of ethnic minority groups, if studies were conducted with different minority ethnic groups, including a matched group from the indigenous population. These studies could then compare awareness, service uptake, stress levels and the experiences of different groups, to discover differences in the use and experience of using services.

This investigation focused on families caring for an adult at home, thus neglecting a
whole section of African/Caribbean carers; e.g. those whose offspring are in receipt of residential placements. An investigation into the experiences, views, opinions and stress levels of this sub-group would add to the very small body of systematic research in this area.

One area of interest as regards the experiences of minority ethnic communities, is that of social support and support networks. As previously noted, there is a popular impression that minority ethnic communities have well-established social networks that they can turn to in times of trouble. Services often perceive these communities as preferring to "look after their own". Ahmad and Atkin, (1996) argue that services will expect to be able to "tap into" this network to facilitate giving people from these communities the support they need. In this study it was speculated that the lower levels of stress reported in this sample, when compared to recent studies with Asian carers and some white carers, might have been influenced by carers' beliefs that they have strong support networks. It would be beneficial to investigate coping strategies in addition to support networks in this group of carers, by using standardised measures to ascertain their impact on stress levels.

This study overlooked those families caring for more than one person with learning disabilities. Although there were two families caring for two people with learning disabilities at home, only the data relating to the eldest sibling was analysed. It would be useful to discover the incidence of carers looking after more than one person with learning disabilities to investigate their experiences.
CLINICAL IMPLICATIONS

Although a high level of awareness was observed in the sample, it is clear that carers felt that in general, African/Caribbean communities are not as aware of the available services as they should be. Carers reported lack of awareness to be the main barrier to service uptake and increasing awareness as the main way to eliminate this barrier. The majority of carers reported that this could be achieved through more publicity generally, but also through mediums, areas and organisations more accessible to the African/Caribbean community. Thus, service providers need to make a concerted effort to inform the community they serve concerning the services that are available.

Carers felt that services could be improved by increasing their cultural sensitivity. This was with regards to culturally appropriate practices and an increase in the knowledge of staff on appropriate ways of caring. Seventy-nine per cent of carers reported that there were no culturally specific activities or practices provided within services. This suggests that services may be adopting the ‘colour blind’ approach, which can serve to disadvantage people from black and minority communities. It is imperative that this area of neglect is addressed.

The Community Care Act (1990) highlighted the requirement for the individual needs of people with learning disabilities to be addressed. Therefore, different cultural practices should not be discouraged or denied, as this can have a detrimental effect on the individual. Services need to make more of an effort to be aware of, and meet the cultural needs of all the users they serve. The implementation of training programmes (e.g., cross-cultural awareness) for staff and managers alike would
facilitate this process.

Within the current sample cultural needs appeared to be related to identity as well as to issues of activities believed to be culturally appropriate (e.g., African and Caribbean cookery and music sessions). It appears important that black people with learning disabilities are exposed to positive images of black people in services. This might be achieved by incorporating into the décor of service buildings (e.g., day centres) posters depicting black images. In addition, the introduction of materials that show positive images of black people; for example, stories about black people and equipment with some images of different ethnic minority people might be useful. This might serve to enhance the self-concept of black people with learning disabilities. In addition, day services could run groups incorporating in their agendas issues that might be important to black service users. Alternatively, black users groups could be introduced in which service users might share experiences and focus specifically on issues important to black users. This might serve to reduce feelings of isolation and increase self-esteem in black service users and result in carers feeling some of their cultural needs are being met by services. Many of these suggestions have already been implemented and are ongoing in some, but not all services.

Previous research has found that the employment of black and minority ethnic staff increases uptake of services within minority ethnic communities (CVS, 1998; Fatimilehin et al, 1998). Carers in this study reported that this strategy would help them to feel more understood, and that their needs were more likely to be met. The employment of more black and minority staff, at all levels of service provision including management, would be beneficial to both services and users alike.
The majority of carers reported that their quality of life would be greatly improved if someone who understood, advised and supported them were allocated to them. This could be implemented by the introduction of black advocates who would then act as a liaison person between carers and services. This approach would mutually benefit carers and services, increasing service uptake and satisfaction.

Given that services do not currently appear to be adequately meeting the needs of African/Caribbean communities, it would be beneficial for them to consult with organisations that appear more able to provide appropriate services, i.e. black voluntary and community organisations (Ahmed et al, 1995; CVS 1998). It appears expedient for services to use this source of information and to implement good practice by convening consultation programmes with these organisations. In this way the knowledge, expertise and practices of these organisations could be used and implemented into mainstream service provision.
CONCLUSION

The study was an exploratory investigation into the nature and level of service use amongst African/Caribbean families caring for learning disabled adults in the home setting. It aimed to elucidate the types and level of services used, in addition to the views, opinions and experiences of a relatively under-researched group.

This study indicates that families from African/Caribbean communities caring for an adult offspring with learning disabilities tend to be living in circumstances of material disadvantage, when compared to the general population. This is consistent with the literature and previous research.

The current study also indicates that although awareness of services in the sample is generally high, uptake of a range of services is comparatively low. Although there was a very low uptake rate of respite care, which is considered to be one vital form of family support, African/Caribbean carers were generally satisfied with the services they received. However, levels of stress were high in the majority of carers and confidence in services was low. The vast majority of carers would not turn to services at times of crisis, preferring to seek informal support.

Despite being satisfied with services generally, carers were aware of and concerned about what was perceived as the lack of cultural sensitivity and culturally appropriate practices currently apparent within services. In addition, carers felt that services were not doing enough to ensure that all sections of the community they served were aware of available services and how they might be able to provide support.
It is important to be tentative about the conclusions that can be drawn on the basis of the current study, due to the highly selected sample used and the lack of comparison group. However, it does appear that, along with other minority ethnic carers, African/Caribbean families caring for a learning disabled adult are a neglected group. Although the present sample tended not to complain about their situation, it seems clear that they would benefit if services were more responsive to their needs.

Further research is required into the service use and experience of African/Caribbean people with learning disabilities and their families so that their needs can be more fully understood and as a result, better catered for. It is of the utmost importance that services work together with families from African/Caribbean communities and black voluntary organisations, in an attempt to find ways to improve service provision in these communities.

Surveys of the prevalence of learning disabilities, in addition to qualitative research into the experiences of African/Caribbean families caring for a learning disabled member, would greatly improve understanding of this group and could assist in the remodelling of services to better meet their needs.

The results of this study suggest that people from minority ethnic groups may still experience double disadvantage, and highlights the slow progress of change. It also highlights the importance of continuing to work towards the ultimate ideal of equitable service provision for all sections of the community.
REFERENCES


APPENDIX 1

LETTERS SENT TO CARERS
Dear Carer,

Yvonne Scarlett, a clinical psychologist in training, has approached us for help with a research project on service usage by African and African/Caribbean adults with a learning disability, and the problems experienced by their carers.

The research involves interviewing carers of African and African/Caribbean learning disabled adults who live at home.

We would like to support Yvonne’s research and it seems from our records that is or has been a user of services from the Community Team for Learning Disability in Wembley. We hope therefore that you might be willing to help Yvonne in her research.

Yvonne will be contacting you shortly. You are of course under no obligation and if you choose not to participate in the study this will have no effect on service provision for your family member.

If our records are incorrect and this letter is inappropriate please accept my sincere apologies.

Yours sincerely,

Kofi Krafona
Chartered Clinical Psychologist.
From: Yvonne Scarlett  
Clinical Psychologist in Training  
University College London  
22 March 1999

Project – Patterns of specialist service use among African/Caribbean families caring for an adult with learning difficulties

Dear Carer,

I am writing this letter to ask for your help with a study I am doing at the moment. The study looks at the services used by black people with learning difficulties and their families. By doing this study I hope to find out more about when black families like yourselves use the different services that are available to them, for example, health and social services and voluntary services such as Mencap or Carer Support groups.

I would also like to learn more about what you think of the services that your son/daughter uses. Also how you think that services might be made better to meet your son/daughter's needs. I will also be looking at the possible problems and stresses faced by carers looking after an adult with learning difficulties at home.

I wanted to look at this area because I had previously worked with people with learning difficulties for a number of years before starting my training and am black myself. I feel it is important that the experiences, views and opinions of black families caring for someone with learning difficulties are brought out and noted. It would help me greatly to bring out these views and opinions if you agreed to talk to me about this study.

At the moment I have no information at all about you and this letter is being sent out by the Resource Team for people with learning difficulties and is therefore completely anonymous. If you would like to find out more about this study (with no obligation to take part) you will need to get in touch with the Resource Team and I will then be able to contact you directly.

Thank you for taking the time to read this letter and I hope to be able to tell you more about the study in the near future.

Yours sincerely,

Yvonne Scarlett
APPENDIX 2

LETTERS OF ETHICAL APPROVAL
Dear Dr Barker

Study No: 98/0130 (Please quote in all correspondence)
Title: Patterns of specialist service use among African/Caribbean families caring for an adult with learning disabilities

Thank you very much for letting me see the above application which has been given Chairman's Approval. You may go ahead with your study.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. Please remember to quote the above number in any correspondence.

Yours sincerely

[Signature]

Professor André McLean
Chairman
03 February 1999

Dr Chris Barker
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT

Dear Dr Barker

Application No: 99/20
Title: Patterns of specialist service use among African/Caribbean families caring for an adult with learning disabilities

I have considered the above application on behalf of the Local Research Ethics Committee, and I am pleased to inform you that this study has been approved.

Please note that the following conditions of approval apply:-

- It is the responsibility of the investigators to ensure that all associated staff, including nursing staff, are informed of research projects and are told that they have the approval of the Ethics Committee.

- If data are to be stored on a computer in such a way as to make it possible to identify individuals then the project must be registered under the Data Protection Act 1984. Please consult your department data protection officer for advice.

- The Committee must receive immediate notification of any adverse or unforeseen circumstances arising out of the trial.

- The Committee must receive notification: (a) when the study is complete; (b) if it fails to start or is abandoned; (c) if the investigator/s change; and (d) if any amendments to the study are made.
The Committee will request details of the progress of the research project periodically (i.e. annually) and require a copy of the report on completion of the project.

Please forward any additional information/amendments regarding your study to the Ethics Committee Administrator, at the above address. If you have any queries, please do not hesitate to contact me.

Yours sincerely

Stephanie Ellis
CHAIR
Ms Yvonne Scarlett
51 Chelmsford Road
Walthamstow
London E17 8NN

Dear Ms Scarlett,

Re: BEC 531: Patterns of specialist service use among African/Caribbean families caring for an adult with learning disabilities.

The Ethics Committee considered your Application at their meeting on 23rd February. Two issues were raised which the committee wanted clarified.

(a) Will carers who are identified as not making full use of the services available, be given advice and information on how to better access services?

(b) As some questions may be sensitive for carers the committee asked if it was necessary for all the questions to be answered.

We have now received satisfactory answers to these queries together with a revised Patient Information Sheet your project can now be approved.

You may proceed on the understanding that the researchers will observe strict confidentiality over the medical and personal records of these patients. It is suggested that this be achieved by avoidance of the subject's name or initials in the communication data. In the case of hospital patients, this can be done by using the hospital record number and in general practice the National Insurance number of a code agreed with the relevant general practitioners.

It should be noted:

1. The Ethics Committee's decision does not cover any resource implications, which may be involved in your project.

2. The Ethics Committee should be informed of any untoward development or changes in protocol that may occur during the course of your investigations. Please quote your BEC Number in any correspondence.

3. Where research involves computer data, this may be subject to the Data Protection Act.

Chairman - Dr Kate Ryan: Administrator - Mrs Beryl Frost
4. The general practitioners of any volunteers taking part in research projects should be aware of their patients' participation.

5. Every care is taken to obtain the volunteers' informed consent to participate in the research project with the necessary help being provided for volunteers with language difficulties.

6. One of the conditions of approval is the provision of a short report when the study has been completed, and we would be interested to know if it had been published in a journal. Perhaps you would be kind enough to let us have this information at the appropriate time.

Yours sincerely,

[Signature]

Dr Kate Ryan
Chairman
APPENDIX 3

INFORMATION SHEET & CONSENT FORM
INFORMATION SHEET

Study Title: Patterns of specialist service use among African/Caribbean families caring for an adult with learning disabilities

PURPOSE

I am inviting you to participate in a study which will look at services used by African/Caribbean families caring for an adult with learning disabilities. It will be looking at when families use different services and why they chose to use the particular services that they use.

WHAT'S INVOLVED?

If you agree to take part in this study, I will come to see you at a convenient location, such as your home or a carers/support group you go to. I will ask you to fill out some questionnaires and there may be a tape recorded interview. It will take about 50 minutes to fill out the questionnaires and 90 minutes to complete the interview. However, the interview will not be carried out on the same day as the questionnaires.

There is no obligation to take part in the study if you do not want to. If you do decide to take part, you may withdraw at any time without giving a reason. You may also skip any questions that you do not want to answer. Your decision not to take part/withdraw will not affect the services that you or your son/daughter receives.

All your identifying details and any disclosed information will be confidential.

If you have any questions you would like to ask regarding the study, please feel free to do so now. Alternatively, you can contact one of the investigators at the address or the number below.

INVESTIGATORS

Ms. Yvonne Scarlett and Dr. Chris Barker
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT Telephone: 0171-380-7897

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Brent Committee on the Ethics of Human Research.
CONSENT FORM

Study Title: Patterns of specialist service use among families caring for an adult with learning disabilities from African/Caribbean backgrounds.

Investigators: Dr. Chris Barker, Sub-department of clinical health psychology, University College London. Ms. Yvonne Scarlett, Sub-department of clinical health psychology, University College London.

Please complete the following: Delete as necessary

1) Have you read the information sheet about this study? YES/NO
2) Have you had an opportunity to ask questions and discuss this study? YES/NO
3) Have you received satisfactory answers to all your questions? YES/NO
4) Have you received enough information about the study? YES/NO
5) Do you understand that you are free to withdraw from this study at any time and without giving a reason for withdrawing without this affecting the care you or your son/daughter receives? YES/NO

6) Which investigator have you spoken to?

7) Do you agree to participate in this study? YES/NO

Signed: ......................................................... Date: ...........................................

Name (Block letters): .................................................................

Investigator: .................................................................
(DAS)

(0 = Not known/not applicable)

MOBILITY

(Is s/he able to walk by him/herself)

1) Non-mobile or needs help walking on flat
2) Needs help upstairs but walks unaided on flat (without aid)
   (Rate 2 if fully mobile on hands and knees)
3) Needs help only because blind or has fits
4) Walks unaided everywhere (without human aid).

CONTINENCE - Including wetting/soiling due to fits

(Is s/he clean and dry? How often does s/he wet/soil?)

<table>
<thead>
<tr>
<th></th>
<th>a) Wetting nights (2...)</th>
<th>b) Soiling nights (3...)</th>
<th>c) Wetting days (4...)</th>
<th>Soiling days (5...)</th>
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<tbody>
<tr>
<td>1) Five or seven times per week</td>
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<td>2) Three or four times per week</td>
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<td>3) Twice weekly or less</td>
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<td>4) Once weekly or less</td>
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<td>5) Never</td>
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</tbody>
</table>

(If variable - average over three months)

e) Toiletting habits
1) Needs daily toileting
   (If verbal prompting needed code 1)
2) Asks to go
3) Goes alone
   (if regularly toileting - ask what happens in times between)
SELF-HELP
(Is s/he able to feed/wash/dress self)

a. FEEDING

1. Not at all
2. With help
3. Without help
   (Code 3 if he/she eats without undue mess, in reasonable time if left alone.
   Also code 3 if food prepared for diabetic or mashed up for other reasons code 3)

b) WASHING (Code as above)
   (Code 3 if he/she can wash self, but (he) has to be shaved)

c) DRESSING
1) Not at all
2) With help (including zips/bra)
3) Without help-but cannot tie shoe laces
4) Without help-can tie shoe laces

VISION, HEARING, COMMUNICATION

A) VISION (Rate with spectacles if worn)
(Is he/she able to see normally?)

1) Blind or almost
2) Poor
3) Normal

B) HEARING (Rate with hearing aid if worn)
(Is he/she able to hear normally?)

1) Deaf or almost
2) Poor
3) Normal
C) METHOD OF COMMUNICATION
(Can he/she speak or gesture? How does he let you know what s/he wants?)
1) Little or nothing, or meaningless echolalia
2) A few sounds or concrete gestures such as pulling you by the hand, pointing.
3) Mostly gestures or signs
4) Mixture of speech and gesture
5) Can make him/herself understood by speech alone

D) UNDERSTANDING COMMUNICATION - Speech, gesture frowning etc.
(Is he/she able to understand instructions? Does he/she understand if you ask him/her about things s/he has done?)
1) Little or nothing
2) Understands a few simple commands
3) Understands a fair range of instructions related to practical needs
4) Understands comments, questions and instructions related to personal needs and experiences (e.g. did you enjoy the trip to the Zoo?)
5) Understands information about things outside his immediate experience (e.g. major items of current news)

E) USING COMMUNICATION - Speech, gesture, drawing etc.
(Can he ask for things s/he wants? Can s/he talk about things s/he has done?)
1) Little or nothing, or meaningless echolalia
2) Uses a few words or signs (e.g. hello, bye-bye, drink)
3) Uses words or signs for practical needs
4) Uses words or signs to comment on his own personal experience (e.g. tells people s/he has new clothes, that s/he has been on an outing, that someone has done something wrong etc.)
5) Can converse, in words or signs, about things outside his own personal experience (e.g. makes comments about items in the news, or about the family of someone s/he knows)

F) PRONUNCIATION - Rate on spontaneous speech, not meaningless echolalia
(How clear is his/her speech? How easy is it to understand?)
0) Not enough spontaneous speech to rate, or only meaningless echolalia
2) Difficult to understand even by close acquaintances. Impossible for strangers
3) Clear enough to be understood by anyone.
SKILLS

A) READING
(Can he read any words?)

1) Has no understanding of written words
2) Can recognize his own name (if written down)
3) Can match words to pictures
4) Can recognize up to ten familiar words
5) Can read and understand simple first reading books
6) Can read and understand books for children aged 7+
7) reads on own initiative

B) WRITING
(Can S/he write any letters of the alphabet or words?)

1) None
2) Can write some letters by copying (If can sign own name code 2)
3) Can write some words by copying
4) Can write some letters without copying
5) Can write a few simple words without copying
6) Can write 12 or more words without copying
7) Can write a short letter on own initiative

C) COUNTING AND MONEY
(Can s/he count, does s/he understand money?)

1) Nothing or can say 1,2,3, with little or no meaning
2) Can at least sort out 4 spoons, 3 sheets, 5 plates etc.
3) Can be sent to shops with money.
   Makes small purchases. If old enough, handles own pocket money or regular allowance.
   (Must be 50p minimum)

D) DOMESTIC SKILLS - Laying tables, washing up, cooking, bed making etc.
(Is s/he able to give any help with clearing up or tidying?)

1) None
2) Sometimes with supervision
3) Works well with little or no supervision
E) HANDICRAFTS - art, pottery, sewing, woodwork, etc. (Is s/he able to do any handiwork or art work?)
Code as above (O - Not known/capable but no opportunity)

F) OCCUPATIONAL SKILLS - Packing, box folding etc. Adults only (Code O for children)
Code as above

BEHAVIOUR PROBLEMS

9) (Does s/he have any behaviour problems? How do you manage when this behaviour occurs? How often does it happen?) Code for items a to n:-

1) Severe management problem (carers have to intervene, or upsets other family members, or marked effect on social atmosphere. Would be unacceptable in public)
2) Lesser management problem
3) Does not occur
4) Potential (Controlled in present environment but very likely to recur as a severe problem if environment changed)

N.B. A behaviour problem may be rated as ' 1 ' either because of its severity when it occurs, or because of its frequency, or both.

a) Physically aggressive to others
b) Destructive - paper furniture, clothing, windows etc.
c) Overactive- paces up and down, does not sit still
d) Seeks attention - pesters others
e) Self injury- head banging, picking sores, biting etc.
f) Wanders or runs away if unsupervised
g) Screams or makes other disturbing noises- shouts, grunts, uncontrollable laughter etc.
h) Temper tantrums or verbal abuse
i) Disturbs others at night
j) Difficult or objectionable personal habits - spits, smears, self-induced vomiting, eats rubbish, continuous eating or drinking, inappropriate swearing or sexual behaviour, hoards rubbish etc., include difficult or objectionable habits with menstruation
k) Scatters or throws objects around - creates chaos aimlessly
l) Anti-social; delinquent - steals, lies, bullies, incites others etc.
m) Sexual delinquency or other problems with social awareness - of no social awareness, code under j.

n) other- specify
**MEDICAL**

**A. EPILEPSY**
(Does s/he have fits? If not, is s/he on any medication to prevent fits?)

1. One or more major seizures per month
2. Medication required or only occasional seizures
3. No medication for fits and no seizures

**B. CHRONIC PHYSICAL DISORDERS - Affecting independence**
(Does s/he have any conditions affecting his ability to move independently, or to look after her/himself?)

1. Yes
2. No

**C. OTHER CHRONIC PHYSICAL DISORDERS - needing medication, etc.**
(Does s/he have any other chronic physical conditions needing regular medication, injection, physiotherapy, nursing care, or other special attention?)

1. Yes
2. No

**D. PSYCHIATRIC CONDITIONS - excluding autism or other childhood psychosis**
(Has s/he had any psychotic or neurotic condition in addition to learning disabilities?)

1. Yes
2. No

**E. ASSOCIATED CONDITIONS OF ETIOLOGICAL SIGNIFICANCE**

0. None identified/not known
1. Downs Syndrome
2. Cerebral Palsy
3. Other identifiable conditions
APPENDIX 5

THE CLIENT SERVICE RECEIPT INTERVIEW
Services received over the past six months

<table>
<thead>
<tr>
<th>Services</th>
<th>A (Awareness?)</th>
<th>B (Access?)</th>
<th>C (Received?)</th>
<th>D (Where?)</th>
<th>E (No of times)</th>
<th>F (Average length of each session)</th>
<th>G (Sufficiency)</th>
<th>H (Quality)</th>
<th>I (Barrier)</th>
</tr>
</thead>
<tbody>
<tr>
<td>01 Hospital in-patient</td>
<td>Y/N</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>02 Hospital out-patient</td>
<td>Y/N</td>
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<td></td>
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<tr>
<td>03 Hospital Day-patient</td>
<td>Y/N</td>
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<tr>
<td>04 G.P.</td>
<td>Y/N</td>
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<tr>
<td>05 Psychiatrists</td>
<td>Y/N</td>
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<tr>
<td>06 Other medical consultant</td>
<td>Y/N</td>
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<tr>
<td>07 Dentist or oral hygienist</td>
<td>Y/N</td>
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<tr>
<td>08 Chiropodist</td>
<td>Y/N</td>
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<tr>
<td>09 Optician</td>
<td>Y/N</td>
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<tr>
<td>10 Audiologists</td>
<td>Y/N</td>
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<tr>
<td>11 Employment Agency</td>
<td>Y/N</td>
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<tr>
<td>12 District Nurse</td>
<td>Y/N</td>
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<td></td>
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<tr>
<td>13 Community Psychiatric nurse</td>
<td>Y/N</td>
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<td></td>
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<td></td>
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<tr>
<td>14 Nursing Auxiliary</td>
<td>Y/N</td>
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</tbody>
</table>
Quality = How satisfied are you with the quality of the service received?

<table>
<thead>
<tr>
<th>15-30 Services</th>
<th>A (Awareness)</th>
<th>B (Access)</th>
<th>C (Received)</th>
<th>D (Where)</th>
<th>E (No. of times used)</th>
<th>F (Average length of session)</th>
<th>G (Sufficiency)</th>
<th>H (Quality)</th>
<th>I (Barrier)</th>
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</thead>
<tbody>
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<td>Community Mental handicap nurse</td>
<td>Y/N</td>
<td>Y/N</td>
<td>R/N</td>
<td>H/E</td>
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<td>Educational Psychologists</td>
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<td>Clinical Psychologists</td>
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<tr>
<td>Speech Therapist</td>
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<td>Physiotherapist</td>
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<tr>
<td>Occupational Therapist</td>
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<td>Support worker</td>
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<tr>
<td>Volunteer visitor</td>
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<td>Advocate</td>
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<tr>
<td>Additional support Team</td>
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<tr>
<td>Respite care (Short-term)</td>
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<tr>
<td>Respite care (Long-term)</td>
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<td>Transport</td>
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<td>Other (specify)</td>
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<td>Other (Specify)</td>
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<td>Other (Specify)</td>
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</table>
APPENDIX 6

QUESTIONNAIRE OF DAY CARE AND RESPITE CARE
Day Care

20) What form of day care does.....................receive currently?

ATC/SEC [ 1 ]
Hospital Unit [ 2 ]
Carers employed [ 3 ]
Further Education [ 4 ]
Other (Specify) [ 5 ]
Receives None [ 6 ]

Number of days per week

Total number of hours per week

If No formal day care received, why not?

a) What was offered was not suitable (State reason) [ 1 ]
b) Didn't like going, wouldn't settle [ 2 ]
c) Inadequate transport facilities [ 3 ]
d) No places available [ 4 ]
e) Parents refused to send [ 5 ]
f) Other (Specify) [ 6 ]

If services could be made more appropriate, would you like .........................to receive day care?
Yes [ 1 ]

If day care received

21) Are there any special arrangements made for .....................'s day care which are different from those which other people receive?


If Yes what are they?

Are the arrangements in any way culturally specific?

22) When did you last discuss ..................... with any one who works with during the day?

Within past week [ 1 ]
Within past month [ 2 ]
Within past year [ 3 ]
D/K C/R . . [ 4 ]
Never . . [ 5 ]
Or [ 6 ]
If never would you have like to?

Yes [1]  No [2]

If yes what prevented you from doing so?

Communication problems
Staff unhelpful and unapproachable
Other (specify)

23) Is alternative care available during the holidays?

No holidays . [1]
Not available . [2]
Yes but do not use it. [3]
Yes, partly. [4]
Yes, fully. [5]

If not available, why not?

Did not know that holiday care service existed [1]
Did not know where to ask for holiday care service [2]
Turned down for holiday care service [3]
Difficult to contact those who supply such services [4]
Provision does not meet our needs [5]
Other (Please specify)

If not available, why not?

If not available, why not?

If not available, why not?

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If not available, why not?

If not available, why not?

If not available, why not?
25) Overall day-care rating

- Sufficiency [ ]
- Quality [ ]

Respite care (short-term)

26) What do you understand by short-term care?

27) If respite care used, could you please tell me how many times a year it was used and what form of service was used.

<table>
<thead>
<tr>
<th>Nights per year</th>
<th>Forms of service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider</td>
<td>Service facility</td>
</tr>
<tr>
<td>Special team</td>
<td></td>
</tr>
<tr>
<td>SSD</td>
<td></td>
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<tr>
<td>NHS</td>
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<tr>
<td>Voluntary</td>
<td></td>
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<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td></td>
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<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Informal</td>
<td></td>
</tr>
</tbody>
</table>
If No short-term respite care, why not?

1) No short term care available - lack of money
2) Not suited to .......'s needs - won't let ............... go
3) Worried about abuse - won't let ............... go
4) Culturally inappropriate i.e. Male carers at the service
5) Culturally inappropriate ways of caring
6) Service provided in inappropriate settings (Specify)
7) Service not flexible enough to provide care for long periods of time
8) Save for emergencies only
9) Facility could not accommodate to ......... 's needs
10) ............... won't go because of unpleasant experience
11) ............... Doesn't like/frets when away from parents and home
12) Other (Specify)

28) Have you met any of the staff who looked after ............... ?


If No would you have liked to?


If Yes what prevented you from doing so?

Communication problems [ 1 ]
Staff unhelpful and unapproachable [ 2 ]
Other (specify) [ 3 ]

29) Are there any special arrangements made for ............... within the residential care services that takes into account ...............'s specific cultural/religious needs. i.e. ways of caring


IF Yes what?
If No would you like them to?


If Yes Specify.

30) How important is it for you that short term residential care should be just specifically for African/Caribbean users cared for by specifically African/Caribbean staff?

1 Very Important [ 1 ]
2 Important . . [2 ]
3 Fairly important [3 ]
4 Not really bothered [4 ]
5 Not important [5 ]

31) Overall rating for Respite care:

Sufficiency [ ]
Quality [ ]

32) What suggestions can you make to make short-term care more appropriate for African/Caribbean people with learning disabilities.

If more than one, rate in order of importance:

1) Family based respite care to be provided within same race families [ 1 ]
2) Same sex carers to users [ 2 ]
3) Same race of carers to users [ 3 ]
4) More awareness of respite care services [ 4 ]
5) More respite care needed [ 5 ]

6) Greater awareness amongst carers
   on culturally appropriate ways of caring [ 6] 
7) More easily accessible ways of getting respite service [ 7] 

8) Other (Specify)
Section D Future care

33) Have you got any plans for ...............'s future

   Yes  [ 1 ]  
   No   [ 2 ]  

If Yes have you discussed it with:

   Yes  No

   Immediate family  [ 1 ]  [ 2 ]
   The extended family  [ 1 ]  [ 2 ]
   Any professional workers  [ 1 ]  [ 2 ]

Are you able to discuss it with ...............?  [ 1 ]  [ 2 ]

34) What do you think will happen about ...............'s future care?

   a) Don't know/still considering options  [ 1 ]
   b) Continue to be cared for by family  [ 2 ]
   c) Want independent living sometime  [ 3 ]
   d) Will need residential placement eventually  [ 4 ]
   e) Will need residential placement soon  [ 5 ]
   f) Will need residential placement now  [ 6 ]
   g) Other (Specify)  [ 7 ]

35) When a residential place is wanted - have you in mind the sort of place you would like?

   Leave home for ...............(Run by MENCAP/SS)  [ 1 ]
   Relatives home with additional support from services  [ 2 ]
   Group homes specially for African/Caribbean people supported with African/Caribbean staff  [ 3 ]
   Residential or group homes provided and supported by services...  [ 4 ]
   Other (Specify)  [ 5 ]

   And where?

   Near to family home  [ 1 ]
   Further away  [ 2 ]
   Unimportant  [ 3 ]
36) How important is it to you that ................. should attend services where s/he will be integrated with people who do not have a learning disability?

- Definitely important [1]
- Preferred but not essential [2]
- Not important [3]
- Prefer not integrated [4]

37) How important is it to you that ................. should attend services where s/he will be integrated with people who are also African/Caribbean?

- Definitely important [1]
- Preferred but not essential [2]
- Not important [3]
- Prefer not integrated [4]

Section E. Carers needs

38) As a carer do you receive any of the following support services?

a) Social worker visits (approximate frequency) [1]
- b) Respite services (specify) [2]
- c) Carer's support group [3]
- d) Other (Specify) [4]
- e) None of these [5]

39) How far do you think your needs as a carer are being met?

a) Completely [1]
- b) Mostly [2]
- c) To some extent [3]
- d) Not at all [4]

40) What other services would better meet your needs or help you to look after the person with learning disabilities?

a) More appropriate support at home [1]
- b) More appropriate support care in respite [2]
- c) Support from other African/Caribbean carers who are in similar positions i.e. a carers group [3]
- d) Someone to understand, advise, support, who? [4]
- e) Other (Specify) [5]
Levels of supervision and flexibility in caring

41) i- Who is mainly responsible for caring for.....
   ii- Who else?

( ) ( )

Mother . .
Father . .
Sister . .
Brother . .
Other relative . .
Other Non-relative (Specify) . .

42) a) In the last month, what is the length of time you have been able to leave unsupervised alone in a room, perhaps watching TV when you are in another room, without going in to check.

Unable to leave for a moment
15 minutes or less
Between 30 minutes and 1 hour
Between 1 and 2 hours
Over 2 hours

b) How much of a problem is this?

Not a problem
a nuisance only
a slight problem
a definite problem

43) If you wanted to go to visit someone

a) in the evening could you? [ Y ] [ N ] [ DK]
b) If you wanted to go away for a weekend, could you? [ Y ] [ N ] [ DK]
c) How achieved?

<table>
<thead>
<tr>
<th></th>
<th>Leave alone</th>
<th>Take in Household</th>
<th>Spouse</th>
<th>Other relative in Household</th>
<th>Other informal</th>
<th>Statutory paid</th>
<th>Voluntary</th>
<th>Other</th>
</tr>
</thead>
</table>

44) If you compare yourself to other parents of your age, does the care of: mean you have to restrict or completely cut out any of the following:

<table>
<thead>
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<th></th>
<th>No effect</th>
<th>Restrict</th>
<th>Completely cut out</th>
<th>Have more</th>
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</thead>
<tbody>
<tr>
<td>Holidays</td>
<td></td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Social outings</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Visiting friends</td>
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<td>4</td>
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<tr>
<td>Pursuing your own interests/hobbies</td>
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<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>Leisure activity at home</td>
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<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

(Malaise Inventory - administer)
45) A. How often have you and your husband consulted your GP during the last year?

Number of consultations in last year:

Wife [ ]
Husband [ ]

B. Have you or your husband/wife had to go hospital as an in-patient or out-patient in the last year?

(Yes) No

<table>
<thead>
<tr>
<th></th>
<th>Wife</th>
<th>Husband</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-patient</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Out-patient</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

C. Do you feel that looking after ......................... is affecting, or has affected your or your husband's/wife's health, physically or in a mental or emotional sense?

<table>
<thead>
<tr>
<th></th>
<th>Wife</th>
<th>Husband</th>
</tr>
</thead>
<tbody>
<tr>
<td>No reported effect on health</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Physical health only</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Mental/emotional health only</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Physical and mental/emotional health</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

D. Have you or your husband/wife suffered any of these health problems?

<table>
<thead>
<tr>
<th></th>
<th>Wife</th>
<th>Husband</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angina</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Anxiety attacks</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Anxious/tense/irritable</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Back problems</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Chest pains</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Depression/weeping</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Heart attacks</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Injury by ..................</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Insomnia</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Nervous breakdown</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Stomach problems</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Stroke</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>tired/distracted</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Ulcer</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Other (Specify)</td>
<td>1 2 3</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

E. Is there someone you can confide in or talk frankly to if anything should worry or upset you about ......................... ?
46) Who would you contact in a crisis?

- Services . . [1]
- Family networks [2]
- Other (Specify) [3]
- DK . . [4]

If services then which type?.................................

47) If you want to ask for help or advice about is there any particular person you would go to in the first instance?

- No one [1]
- Family [2]
- Statuary [3]
- Voluntary [4]
- Others [5]

48) In your opinion why do you think that people from the African/Caribbean community may not be using the services available for people with learning disabilities? Is it because:

1) Lack of awareness of services [1]
2) Discrimination in service provision [2]
3) Culturally inadequate and inappropriate services [3]
4) Other (Specify) [4]

49) What problems have you encountered when dealing with service providers:

50) How confident do you feel that something will be done to help if you approach services with a problem?

- Very confident [1]
- Fairly confident [2]
- Confident . . [3]
- Not confident [4]
- Not confident at all [5]
- Don't know . . [6]
51) Overall how satisfied are you with the services you are receiving?

Not receiving enough services to comment [0]
Very satisfied [5]
Satisfied [4]
Neither [3]
Dissatisfied [2]
Very dissatisfied [1]

52) In your opinion what might be done to improve the quality and access of services so that African/Caribbean people will use the Learning disability services provided?

More African/Caribbean staff in learning disability services [1]
More publicity of the services in Black media [2]
Culturally sensitive services [3]
Support networks [4]
Others (Specify) [5]

53) Is there anything else you would like to tell me about services for African/Caribbean people with learning disabilities?

(Ask only if applicable) Would you be interested in participating in a further detailed interview to discuss some of these issues in more depth?

Yes [1]
No [2]
44) a. Now I would like to ask you about particular problems you may have had recently with your health.

(MI)

Please circle either Yes or No for each item.

1) Do you often have a back ache   Yes  No
2) Do you often feel tired most of the time   Yes  No
3) Do you often feel miserable or depressed   Yes  No
4) Do you often have bad headaches   Yes  No
5) Do you often get worried about things   Yes  No
6) Do you usually have great difficulty falling a sleep   Yes  No
7) Do you wake unnecessarily early in the morning   Yes  No
8) Do you wear yourself out worrying, about your health   Yes  No
9) Do often get into a violent rage   Yes  No
10) Do people often annoy or irritate you   Yes  No
11) Have you at times had a twitching of the face, head or shoulder   Yes  No
12) Do often suddenly become scared for no good reason   Yes  No
13) Are you scared to be alone when there are no friends around you   Yes  No
14) Are you easily upset or irritated   Yes  No
15) Are you frightened of going out alone and meeting people   Yes  No
16) Are you constantly keyed up and jittery   Yes  No
17) Do you suffer from indigestion   Yes  No
18) Do often suffer from upset stomach   Yes  No
19) Is your appetite poor   Yes  No
20) Does every little thing get on your nerves and wear you out   Yes  No
21) Does your heart often race like mad   Yes  No
22) Do you often have had pains in your eyes   Yes  No
23) Are you troubled with rheumatism or fibrositis   Yes  No
24) Have you ever had a nervous break down   Yes  No
APPENDIX 8

SHORT FORM OF THE QUESTIONNAIRE ON RESOURCE AND STRESS
RESOURCES AND STRESS QUESTIONNAIRE

This questionnaire deals with your feelings about your son/daughter. There are many blanks on the questionnaire. Imagine your son/daughter's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or false, even then. Remember to answer all of the questions.

1. ------- doesn't communicate with others of his/her age group. T F

2. Other members of the family have to do without things because of---------. T F

3. Our family agrees on important matters. T F

4. I worry what will happen to -------, when I can no longer take care of him/her. T F

5. The constant demands for care for -------, limit growth and development of someone else in our family. T F

6. ------- is limited in the work that s/he can do. T F

7. I have accepted the fact that ------- might have to live out is/her life in some special setting (i.e. group home). T F

8. ------- can feed him/herself. T F

9. I have given up things I have really wanted to do in order to care for ------- T F

10. ------- is able to fit into the family social group. T F

11. Sometimes I avoid taking ------- out in public. T F

12. In the future, our family's social life will suffer because of increased responsibilities and financial stress. T F

13. It bothers me that ------- will always be this way. T F

14. I feel tense whenever I take ------- out in public. T F

15. I can go and visit friends whenever I want. T F

16. Taking ------- away on holiday spoils pleasure for the whole family. T F

17. ------- knows his/ her own address. T F

18. The family does as many things together now as we ever did. T F

19. ------- is aware who s/he is. T F

20. I get upset with the way my life is going. T F

21. Sometimes I feel very embarrassed because of -------. T F

22. ------- doesn't do as much as s/he should be able to do. T F

23. It is difficult to communicate with ------- because s/he has difficulty understanding what is being said to him/her. T F

(Please turn over)
14. There are many places where we can enjoy ourselves as a family when ________ comes along.

25. ____________ is over protected.

26. ____________ is able to take part in games or sports.

27. ____________ has too much time on his/her hands.

28. I am disappointed that ____________ does not lead a normal life.

29. Time drags for ____________, especially free time.

30. ____________ can't pay attention very long.

31. It is easy for me to relax.

32. I worry about what will be done with ____________ when s/he gets older.

33. I get almost too tired to enjoy myself.

34. One of the things I appreciate about ____________ is his/her confidence.

35. There is a lot of anger and resentment in our family.

36. ____________ is able to go to the bathroom alone.

37. ____________ cannot remember what he/she says from one minute to the next.

38. ____________ can ride a bus.

39. It is easy to communicate with ____________.

40. The constant demands to care for ____________ limit my growth and development.

41. ____________ accepts him/herself as a person.

42. I feel sad when I think of ____________.

43. I often worry about what will happen to ____________ when I can no longer take care of him/her.

44. People can't understand what ____________ tries to say.

45. Caring for ____________ puts a strain on me.

46. Members of our family get to do the same kinds of things other families do.

47. ____________ will always be a problem to us.

48. ____________ is able to express his/her feelings to others.

49. ____________ is able to use a toilet.

50. I rarely feel blue.

51. I am worried much of the time.

52. ____________ can walk without help.
APPENDIX 9

DEMOGRAPHIC CHARACTERISTICS
Demographic information
If it is OK, I would like to begin by asking you some questions about you and your family, which shouldn’t take long.

a) What is your marital status?
1) Married  
2) single  
3) divorced  
4) separated  
5) widowed  
6) cohabiting  

b) How old are you?  
   (Age of primary Carer)  
   _________ Years

c) How old is your relative?  
   (Age of adult with learning disabilities)  
   _________ Years

d) Is there anyone at home that you share the care of ____________ with?
1) Yes  
2) No  

 e) If yes, what is your relationship with this person?
   1) partner  
   2) son/daughter  
   3) sister/brother  
   4) mother/father  
   5) friend  
   6) other, please specify ____________________  
   7) not applicable

f) How old is this person  
   _________ years

g) How would you rate your health?
0) poor  
1) fair  
2) good  
3) excellent

h) How would you rate the health of your relative?
0) poor  
1) fair  
2) good  
3) excellent

i) How many siblings do your relative have? ______

j) How old are the siblings?  
   _______ and _______ and _______ and _______
k) Do any of the siblings still live at home?
1 yes
2 no

l) If so how many ____________________________

m) What is their occupation ____________________________

n) Are you currently employed?
1 yes
2 no
3 retired – what was your occupation ____________________________

o) If yes what is your occupation? ____________________________

p) If yes, is this full or part time?
1 full time
2 part time
3 not applicable

q) Is your partner employed?
1 yes
2 no
3 retired
4 not applicable

r) If yes, what is his/her occupation? ____________________________

s) If yes, is it full or part time?
1 full time
2 part time
3 not applicable

I’m just about to ask you about your living and financial situation. The reason is that previous research suggests that if people experience any financial difficulties, then this often can be an added worry and concern. If you do not wish to answer some of these questions that is OK.

t) Housing – Is your home
a) Owner occupied [ 1 ]
b) Rented from council [ 2 ]
c) Privately rented [ 3 ]
d) Other [ 4 ]

u) How many rooms are there in your home? (Not counting bathroom and toilet)

v) Does the family have a car? Yes [ 1 ] No [ 2 ]

w) Does your house have a garden Yes [ 1 ] No [ 2 ]


x) Are your housing needs adequate for you and your family’s needs?
   1) Adequate  2) Slightly inadequate  3) Moderately inadequate  4) Severely inadequate

y) Which of the following benefits do you know about, and receive

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Know of</th>
<th>Receive</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability living allowance</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Invalid care allowance</td>
<td>[ ]</td>
<td>[ 1 ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>Income support</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

z) Finance, Is the money coming in adequate for you and your family’s needs?
   1) Adequate  2) Slightly inadequate  3) Markedly inadequate  4) Severely inadequate

a(i) Income could you please give me a rough approximation of the household yearly income.

   1] Less than £10,000
   2] £10,000 - £12,500
   3] £12,500 - £15,000
   4] £15,000 - £17,500
   5] £17,500 - £20,000
   6] £20,000 - £22,500
   7] £22,500 - £25,000
   8] £25,000 - £30,000
   9] £30,000 - £40,000
  [10] £40,000 - and above

b(i) Do you experience any financial difficulties?
   1  yes
   2  no

c(i) Do you have any difficulties in meeting bills and other financial commitments?
   1) No difficulty  2) Slight difficulty  3) Marked difficulty  4) Severe difficulty

d(i) What ethnic group would you consider yourself and your relative as belonging to?

e(i) Number of years resident in the UK?  [   ]

f(i) What was the diagnosis (if any) that was given to your relative?
   1  cerebral palsy
   2  epilepsy
   3  autism
   4  downs syndrome
   5  other
   6  not known
VOLUME 2

CASE REPORTS
AND
SERVICE RELATED RESEARCH

YVONNE SCARLETT

D.Clin.Psy 1999
University College London
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CASE STUDY 1:

BINGE-EATING IN OBESITY,

BINGEING IN RESPONSE TO INTERPERSONAL DIFFICULTY
INTRODUCTION
This case was chosen because it is interesting and illustrates the way in which therapy can be viewed as ongoing assessment, and how new information acquired during the course of therapy can lead to a revision of the formulation. Initially this case was treated as a weight problem; partly due to the information the client brought and partly due to her desire to work at a symptomatic level in order to alleviate her level of distress. As further information emerged this necessitated a revision of the formulation of the problem which gives some indication of why the intervention employed was only partially successful.

REASON FOR REFERRAL
P was referred by her GP who was concerned about her obesity and depression. He reported that P experiences intense food cravings during bouts of “severe depression” in which she can consume 15 bars of chocolate a day. The client viewed this depression as dating back to the birth of her children but had only recently presented to him. He prescribed anti-depressant medication but felt that her obesity and depression might be further helped by psychological intervention.

INITIAL PRESENTATION
P is a 32-year-old Caucasian woman who is married with three children. She described herself as suffering from Seasonal Affective Disorder (SAD), and reported that she gets very depressed in winter; however, she also noted that she sometimes feels depressed during the summer. P feels that she has experienced SAD since the birth of her three children seven to nine years ago. At this time she also gave up a
“highly paid” job to look after the children and run the family’s business which is in the building trade.

P described her main concern as being her eating and reported that her appetite for chocolate increases when she is depressed; this results in the consumption of large quantities of chocolate which she described as “going on a binge”, only stopping when her stomach feels very uncomfortable. This eating pattern has resulted in significant weight gain that has impacted negatively on her self-esteem. P also described bingeing in response to feeling stressed.

She reported that one of the main sources of stress is having to take responsibility for the everyday running of the business in the context of long-term financial difficulties. The second significant source of stress is interpersonal difficulties with her husband and family or origin.

**RELEVANT BACKGROUND INFORMATION**

P was the youngest of three children and had an older brother and sister. Her brother died when she was very young, after this her parents split-up and her mother later remarried. Her mother and stepfather had two children (both girls) and her stepfather adopted P and her biological sister.

P reported that she’d always had a weight problem and said she was a “fat” child. This she attributed to her family overeating, and there being no control over food in their house; all P’s family struggle with their weight. P mentioned that at times during her childhood she had felt belittled by members of her family.
Recently a serious disagreement has occurred between her husband and her family that P feels has placed her in a difficult position and led to increased bingeing. This has resulted in P being caught in the middle with torn loyalties but feeling that neither party was taking her feelings into consideration. This extra stress motivated P to consult her GP.

ASSESSMENT

From assessment it was apparent that her difficulties involved more than just her eating behaviour. There appeared to be three inter-related elements, recent interpersonal difficulties; negative cognitions and accompanying low mood; and the eating behaviour. Although her GP described her as experiencing bouts of severe depression, and P herself felt she was suffering from SAD, from the information gained it was impossible to ascertain whether she would qualify for a diagnosis of depression. It appeared important to explore her early life events and how these may be related to her current difficulties. However, it became apparent that those areas of her life were not open to discussion as she felt they had no bearing on her present situation. P gave clear indications that she wanted to focus on the eating problems.

THEORY

McManus and Waller (1995) proposed a developmental model of binge-eating that is presented within a functional analysis paradigm. This model is concerned with the function of binge-eating behaviour (not a particular syndrome), and pulls together common themes that have been extracted from many recent models of binge-eating behaviour whether or not accompanied by purging behaviours. Two common themes
are 1) binge-eating can occur as a consequence of emotional difficulties or specific eating behaviour, and 2) this behaviour is maintained by the reinforcing effects of its immediate consequences.

Many theorists argue that some of the antecedents of binge-eating are increased stress, negative affect e.g., anxiety, depression (e.g., Beebe 1994; Fairburn et al 1993); interpersonal conflicts, and deficient coping skills (e.g., Loro & Orleans 1981; Lacey et al 1986). The coping value of bingeing in terms of emotional regulation is emphasized (at least in the short-term), as negative affect appears to significantly decrease during and following an episode of bingeing.

This relief from negative emotions (albeit temporary) is a powerful reinforcer maintaining this behaviour. Therefore, interventions that target maladaptive eating behaviour in which bingeing is present, need to address such factors as individuals coping skills; teaching or encouraging the use of more adaptive methods of dealing with stressful events and negative affect alongside eating behaviours. Many of the cognitive-behavioural programs used to intervene with bulimia and obese binge eaters covers the aforementioned areas. As the difficulties being experienced by this client appeared to resemble some of the features of this model, it would seem appropriate to use interventions which have been formulated with these models in mind.

Preliminary Formulation

Clearly events such as those experienced by P in her early childhood potentially have implications for the development of later difficulties if not resolved. The death of a
sibling in her formative years followed by the break up of the family unit would have potentially resulted in major disruption of her environment. The concomitant stress is likely to have had an effect on her development at a variety of levels including the manner in which she copes with stress. However, it was not possible to make any reliable assessment of the effect of her early experiences due to P's resistance to any exploration of these areas.

P appears to use eating as a coping method in response to difficulties she experiences in her everyday life. In particular, she appears to utilise eating as a method of coping with stressful events and negative emotions. It is possible that this is a long-standing pattern that was developed in childhood or early adolescence which may have been acquired through observational learning, perhaps from her parents or other family members.

Although she regards her eating problems as dating back to nine years ago, following a series of life changes, it is possible this pattern is of a more long-standing nature. However, the increased stress and negative mood at this time resulted in the use of eating as a coping strategy becoming more pronounced and frequently used, which resulted in significant weight gain; this in turn impacted on P's self-esteem which ultimately exacerbated her low mood. Although P feels that her eating is the primary problem, it appears that the main problem is her perception of the way she is treated in her interactions with significant others. Her perceptions generate negative cognitions, which in turn produces low mood. She employs eating in an attempt to escape from negative cognitions and affect in addition to comforting herself. This is only effective in the short-term, in the long-term it ultimately reinforces her negative
cognitions, leading to a vicious cycle. This mechanism appears to be operating in her current interpersonal difficulties with her husband and family.

**INTERVENTION**

Initially P was offered a place on a 20-session weight control group for binge eaters, however she declined this offer on the grounds that she felt unable to work effectively within a group setting. She was therefore offered 10 individual sessions over a four-month period.

It seemed important for there to be some discussion and exploration of the way in which P’s early experiences and later interpersonal problems may have contributed to her present difficulties. However, as mentioned before, due to P’s resistance this did not appear to be possible. Therefore, it was decided, in consultation with my supervisor to work at the symptomatic level to address P’s eating problem in the interest of engaging her in therapy. It was anticipated that elements of the cognitive behavioural approach would indirectly address some of her concurrent difficulties.

During the early part of therapy there were indications that her problems were of a more long-standing nature. Initially we attempted to focus on the eating behaviour, but as more information was revealed that suggested the presence of long-standing and pervasive interpersonal difficulties, this indicated a picture more complex than was originally formulated. As the intervention progressed these issues became more salient; as a result it proved impossible to move onto subsequent stages of the intervention. Therefore, the focus was changed in order to help P find ways of dealing more effectively with her current interpersonal difficulties. In the limited
time available it was only possible to address some of her interpersonal difficulties at a relatively superficial level. The skills P wished to acquire involved learning to express her emotions appropriately and learning to "stand-up" for herself. Therefore, the remaining sessions focused on certain aspects of assertiveness training and problem solving skills.

REFORMULATION AND CRITICAL REVIEW

Description of further problems: During the initial stages of treatment it became apparent that P's difficulties were not related solely to recent life events but were of a more long-standing nature. P reported that as a child she had felt her stepfather treated her differently to her siblings. Her stepfather would tell her that "she should be grateful that she had a dad". P felt that her mother, rather than support her, colluded with her stepfather.

P reported that her relationship with her parents left her feeling insecure and unable to interact effectively with others including her peers. In this context she recalled being bullied at school and feeling unsupported by teachers and family. This resulted in her feeling rejected by her family and peers, leading to feeling unloved and unlovable; as a consequence she concluded that she must be defective in some way. She recalled that the only time she felt accepted and loved by others was during her teenage years when she was able to lose and maintain weight loss over a number of years. Many positive events coincided with "being slim", e.g., development of a close relationship with a peer, increased independence from family and the establishment of a long-term sexual relationship that led to marriage, therefore at this time P received considerable reinforcement. She added that her current relationship
with her parents and sisters continue to be problematic and that she sometimes withdraws from them in order not to be hurt. P reported that they currently “put her down”, and call her names regarding her weight.

She also described difficulties communicating her wants and needs to her husband, whom she perceives as inconsiderate of her needs and wishes when dealing with conflicts with her family of origin. She noted that both her family and her husband do not take her opinions seriously and always expect her to compromise. She reported feeling angry and resentful about her inability to assert herself and express her wants and needs.

CONCLUDING FORMULATION

The experience of severe disruption of her physical, social and emotional environment in very early childhood if unresolved is likely to have had a far-reaching effect on P’s way of functioning. She experiences widespread and long-standing difficulties in her interpersonal relationships. These appear to stem from early experiences of feeling ignored and rejected by her family. This led to the formation of core beliefs relating to “unlovability/defectiveness” and therefore, the assumption that she is fundamentally unlovable with the expectation of ultimate rejection. Her core beliefs were confirmed by the treatment she suffered at the hands of her peers. These experiences had a significant effect on her self-esteem leading to long-lasting relationship difficulties. However, during her adolescence the occurrence of positive events following weight loss, resulted in P associating “being slim” with being accepted and loved.
Over the years she coped with these feelings of unlovability by withdrawing from important relationships; this in turn caused others to withdraw from her, ultimately leaving her feeling rejected and confirming her beliefs that she is not good enough and unlovable. P also attempted to counteract these feelings of unlovability by nurturing herself with food; however, this led to significant weight gain and therefore, to the reinforcement of her belief that she is defective and will be rejected by others. These core beliefs are evidenced by dysfunctional assumptions such as: “if I don’t give in to others I will be rejected”, and “if I am slim people will accept and love me”.

The recent family discord appears to have reactivated her unlovability schema, which has generated the previously mentioned negative thoughts. These cognitions impact on her mood and indirectly on her eating behaviour that ultimately reinforces the cognitions, thus perpetuating a vicious circle.

CRITICAL REVIEW

In hindsight there were many complex issues involved in this case which the therapist was not fully aware of at the assessment stage. This is evidenced by the fact that the initial formulation required considerable revision and elucidates why the intervention was only partially successful. However this case does show the way in which intervention can be viewed as ongoing or extended assessment in complex cases.

In hindsight it is clear that the initial emphasis may have been inappropriate for this client’s particular needs although it reflected her wishes, it did not afford the most
beneficial outcome. The formulation indicated that the root of her difficulties resided in the way P perceives how she is treated in her interactions with others; and the cognitive distortion regarding this which results in depression and overeating, therefore the aforementioned issues needed to be addressed.

Although she presented with an eating problem and it was initially treated as such, the therapist was aware that there were other issues but the client made it clear that this was the level she wanted to work at. Therefore in the interest of fostering a good therapeutic alliance and engaging her in the process, it seemed appropriate and good practice to acquiesce to her wishes. However, with the above decision it could have been anticipated that the client might experience difficulty adhering to an eating programme due to the many secondary gains of bingeing i.e., positive feelings from eating foods she enjoys and the reduction of negative emotions.

The therapist did not fully take into account the importance of other factors and did not give interpersonal difficulties enough weight or probe enough at the assessment stage, and therefore was not fully aware of their significance until later. In this case the reformulation clearly shows that P’s eating behaviour was only the symptom indicating that she had more serious underlying difficulties. Therefore if the symptom is treated without addressing the causes the problem is not likely to be fully resolved, because the real issue is not being addressed as is borne out in this case.

Some potentially important factors were not explored because P was not prepared to e.g., her very early experience. One could hypothesise that the underlying reason for this was that it was actually too painful for her to get in touch with her feelings at
this point in time. With longer-term therapy she may have felt safe enough and more able to explore this area. In the light of the reformulation and the salient issues elucidated, perhaps psychodynamic therapy or schema focussed work would have been more appropriate and efficacious. However, the orientation of the psychology department in which this work was carried out was mainly cognitive-behavioural, in conjunction with the therapists level of training (this was one of the therapists first cases), highlights the improbability of the aforementioned therapeutic approaches being offered in this instance.

Due to the limited number of sessions it is improbable that these complex problems would have been effectively addressed. In retrospect, in ideal circumstances this client would have been offered medium to long term work to address her long standing and pervasive interpersonal difficulties. Throughout the course of therapy she only mentioned one person with whom she had favourable interactions and seemed to have major conflicts within all her other relationships. This attests to the reformulation being reasonably accurate in identifying the core issues for this client.

One of the factors that may have been relevant in the outcome of this case is the inexperience of the therapist, this being one of her first cases. The benefit of greater experience may have led the therapist to be more aware of the signs that are indications for longer term work and when to refer on to a senior colleague or an agency specialising in long term psychotherapy. Furthermore, within the current climate in the NHS it appears to be increasingly difficult for clinical psychologists to justify the cost effectiveness of long term work although there is an ever-constant need for it.
Supervision afforded me the opportunity to safely express and explore my doubts and anxieties about working with complex problems. It also provided support with employing relatively unfamiliar techniques. Finally, supervision was very valuable in elucidating theory practice links. Although some cases are not straightforward and may be difficult to conceptualise, perhaps these are the cases that one learns most from as they require much questioning and thinking around the issues by virtue of this. The present case, although very difficult, afforded me much valuable experience.
REFERENCES


CASE STUDY 2:

BEHAVIOURAL MANAGEMENT OF MEALTIME DIFFICULTIES IN A
PRE-SCHOOL CHILD
REASON FOR REFERRAL

Sophie was referred to the eating disorders clinic by a consultant paediatrician, due to her refusal to eat. Sophie’s weight was on the 25th percentile and her height on the 75th percentile, her mother was extremely anxious. Sophie’s mother had sought help at this point due to her concern about Sophie being under nourished, and worry about the reasons she refuses to eat. This difficulty emerged as a problem 13 months previously during mother’s second pregnancy and she is now pregnant again.

PROBLEM DESCRIPTION

Sophie’s mother reported that the main problem was Sophie’s refusal to eat at mealtimes, which were accompanied by difficult behaviour and crying. Mother expressed concerns about the small quantity being consumed and began giving Sophie biscuits between meals to ensure she was eating enough. She was also upset by her daughter’s explanation of why she did not wish to eat. When questioned Sophie would say that she did not want to eat because she “did not want to get fat or have a baby in my tummy”.

Her mother reported that Sophie had tried many tactics to “get out of eating” including spilling drinks over herself and hiding food. This pattern occurs across situations and individuals. Mother described all meals as difficult but the worst was reported to be tea time.

Mother expressed concern that Sophie’s brother was now coming to the age when she felt he might begin to copy Sophie’s behaviour. Mother is also aware that she is
becoming more anxious about meal times and is concerned about her level of tension and anger.

Sophie’s mother has a friend whom Sophie idolizes, who is described as ‘tall, very slim and pretty and never overeats’. Mother reports that Sophie has expressed a desire to be just like this friend. Mother reported that mealtimes were the only difficulty being experienced with Sophie, otherwise she was described as a sociable and friendly child who has an “excellent” relationship with her brother.

BEHAVIOUR AND APPEARANCE

Sophie is a 4½ year old Caucasian girl who seemed healthy in appearance and had a pleasant manner in sessions. She seemed to desire and respond well to praise in sessions. She seemed to compete with her brother for materials in the room and their parent’s attention. In one session Sophie voiced a desire to change her surname to have the same name as the rest of her family.

Mother - Sophie’s mother is in her mid thirties. She initially appeared quite anxious and somewhat unsure of herself. She reported problems being consistent with Sophie at mealtimes. Although not unaffectionate to Sophie, in sessions much of the interaction seemed to be dominated by negative commands.

Stepfather - Sophie’s stepfather is in his mid thirties. He appeared more confident than his wife and was firmer with Sophie. He talked over his wife on a number of occasions and made negative comments about her interaction with Sophie that led to
a disagreement. Although he was not unaffectionate towards Sophie, more attention was given to the brother.

**Brother** - Sophie’s brother is approximately 11 months old, he had a cheerful and engaging manner, actively explored the room and tried to join in or take whatever materials Sophie was using.

**ASSESSMENT**

There were two assessment sessions, the first conducted jointly with a senior dietitian. I later saw the family to address the management of mealtime difficulties and gain some background information. Mother was requested to monitor mealtimes over a two-week period. This consisted of a daily diary and ABC charts which would form a baseline. Within the daily diary mother was asked to rate and record on a scale of 0 to 10, 1) how difficult she found Sophie’s behaviour over each meal-time, 2) how distressed Sophie became, and 3) how distressed mother felt at each meal time. Results showed that over the baseline period the ratings for each of the above ranged from 7 to 10.

Sophie was observed in the clinic setting interacting with her parents and brother and also over a tea time meal with her mother. These baseline assessments suggested that there was a strong behavioural basis to Sophie’s eating problem. Mealtimes varied in duration between 70 and 150 minutes and although these times were in general very tense, Sophie received constant and individual attention.
RELEVANT BACKGROUND INFORMATION

Mother reported an unremarkable pregnancy and birth. At birth Sophie's weight was on the 50th percentile, one month later she was on the 25th percentile where she has remained since. Sophie reached her milestones within the normal time-scale and experienced no major illnesses. Her mother reports that “Sophie was always a slow eater”. Many changes occurred for the family over the course of therapy that resulted in them feeling more settled. They moved house; Sophie’s mother also married the stepfather whose appointment to the army was made permanent. Sophie’s mother works shifts including weekends, therefore she is not present for meals at weekend.

The relationship between Sophie’s biological parents was described as “difficult”, it broke down and father left the family home when Sophie was two years old. After which the relationship between Sophie and mother became very close. Sophie’s mother and stepfather have been in a relationship since she was three years old.

Mother described Sophie’s eating difficulty as dating from the latter stages of her pregnancy with Sophie’s brother and continued after the birth. She decided to seek help when Sophie’s refusal to eat became consistent at all meals and across individuals in and outside the home. Time taken to complete meals occupied large amounts of parental time and energy. Mother was concerned because she felt that Sophie was not eating enough to satisfy her nutritional needs. Concern also grew due to Sophie’s beliefs about the consequences of eating. Mother reported that the parents would manage mealtimes by having one parent responsible for Sophie’s eating, but sometimes the other parent would take over if the first felt unable to
manage. The aforementioned resulted in Sophie gaining individual attention from one or both parents.

THEORY

Behaviour theory proposes that maladaptive behaviour does not differ by and large from adaptive behaviour, in its development, persistence and the way it can be changed. Social learning theorists such as Herbert (1991) suggests that disorders of childhood are essentially exaggerations, deficits or handicapping combinations of behaviours that are common to all children. Maladaptive behaviours are learned in the same way as adaptive ones and are therefore subject to the same principles and laws. The underlying assumption of behaviour theory is behaviours are learned and maintained through the processes of classical and operant conditioning. By definition learned behaviour can be unlearned. The principles of operant conditioning states that behaviour becomes more frequent if they are reinforced, i.e., rewarded. For most pre-school children parental attention is a powerful reinforcer that can serve to maintain behaviour. Behaviour theorists propose that learning does not only depend on the associations made between stimuli and responses but can also occur vicariously on the basis of imitation (Herbert 1991). Children are more likely to imitate behaviour if they see that it has rewarding consequences.

According to behaviour theory avoidance can serve to maintain maladaptive behaviour. In this case the behaviour of avoiding eating serves to maintain and reinforce maladaptive cognitions regarding eating, because the distorted cognitions remained unchallenged.
Social learning theory stresses the active nature of learning that emphasizes the social context in which behaviour is learned. The impact the child (temperament and behaviour) has on its environment as well as the effect the environment has on the child is taken into account creating an interactional relationship (Herbert & Iwaniec 1980). For the pre-school child its environment consists largely of the immediate family, the social situation in which the family exists, and specifically family dynamics and parenting behaviour. Here problems are not regarded as residing solely within the child but is contingent upon what has been learned within the social environment. This suggests that even something as physical as eating or as intangible as beliefs about eating can be learned (Iwaniec & Herbert 1982). Social learning theory also takes account of cognitions and meaning and is therefore robust in explaining how behaviour is learned (Herbert 1981).

The difficulties being experienced by Sophie and family can be usefully conceptualized within a social learning framework. Her beliefs about the negative consequence of eating can be seen as a result of vicarious learning. It also appears that avoidance has a powerful role in maintaining the distorted cognitions regarding eating, which serves in turn to reinforce non-eating behaviour. Sophie's difficult behaviours and refusal to eat at mealtimes can be seen as being maintained on a positive reinforcement schedule where there are many gains from her refusal to eat, while eating has negative consequences.

FORMULATION

At around two years of age ‘difficulties’ in the relationship between her biological parents culminated in her father leaving the family home. There followed a period of
one year in which Sophie shared an exclusive relationship with her mother. At the age of three her mother established a new relationship resulting in the loss of their exclusive relationship. During the later stages of mother’s second pregnancy Sophie would have had to again adapt to reduced attention. With the arrival of her brother Sophie had another rival for her mother’s attention.

Mother’s long-standing concern about Sophie’s eating meant that much attention was paid to any difficulties at mealtimes. As time passed, mother’s concern heightened which led her to employ many strategies to encourage Sophie to eat. Therefore, parental attention served to maintain and increase Sophie’s strategy for gaining attention. Sophie learned that if she refused to eat she could secure much attention that was possibly scarce at other times. Mother “bribes” Sophie with the promise of treats to encourage her to eat. Sophie therefore has much to gain by continuing this behaviour which has generalized to other significant adults. This fits with Linscheid and Rasnake’s (1985) hypothesis that the length of mealtime is a good indication of a behaviourally based eating problem. Although mealtimes were described by mother as very tense and unpleasant, Sophie was aware that if she protested and refused for long enough there was a probability that mother would give in.

Sophie’s verbal expressions about eating served to increase her mother’s anxiety. It is possible that these were learned vicariously, e.g., “if you eat you get a baby in your tummy” possibly by watching mother eat, her stomach swell, then a baby being produced. In the absence of any other clear and constant message about where babies come from, Sophie may have come to her own conclusions.
INTERVENTION

Over a four-month period Sophie was seen on five occasions. This included one session attended by her stepfather. Sophie’s mother was seen an additional two times without Sophie. The dietitian and pediatrician managed the dietary, height and weight aspects of Sophie’s difficulty. My remit was to address the mealtime behaviour problems.

Behavioural management strategies for addressing meal-time difficulties were provided within a social learning framework which was informed by the work of Herbert (1981), Iwaniec and Herbert (1982). Interventions designed to remediate problems such as those being experienced by Sophie and family involves training or retraining, highlighting the need for change in parent behaviour, as well as a change in the child’s behaviour. Similarly, Douglas (1989) suggests that basic behavioural interventions with parents are more successful when they consist of a mixture of behaviour management skills, reassurance, nutritional help, and the facilitation of parental confidence in dealing with their child’s difficult behaviour alongside assistance to improve the parent-child relationship.

A program was set up to reduce the duration of tension surrounding meal-times while ensuring that Sophie received positive attention at other times.

Differential attention - parents were instructed to ignore non-eating behaviour, it was hoped that ignoring difficult behaviour would serve to reduce the tension around meal-times in addition to extinguishing undesirable behaviour. Secondly, parents
were asked to praise Sophie for eating, this would highlight the part that attention plays in reinforcing behaviour.

**Stimulus control** - meals were only to be presented at the dinning room table so that discriminative learning might occur.

**Positive reinforcement** - in addition to the verbal praise given at mealtime, a star chart was used. These stars could be exchanged for a treat at the end of the week.

**Removal of meal** - parents were instructed to remove and throw away food if Sophie was still refusing to eat after 30 minutes, and not to offer any additional food until the next meal-time, allowing her appetite to develop.

**Special time for Sophie** - parents were encouraged to spend sometime each day exclusively with Sophie to play with her or engage in activities she enjoys. Short periods of time 15-20 minutes initially, increasing over time. At this time one or both parents would interact with Sophie. It was hoped that this attention would improve the quality of interactions, in turn improving parent-child relationships. The exclusive attention being gained should allow Sophie to receive the attention she desires and make redundant the need to gain negative attention through her eating behaviour.

**Parental consistency** - parents were encouraged to adopt a joint strategy for dealing with Sophie’s mealtime behaviour that they were both to employ consistently. This would reduce the opportunity for Sophie to control mealtimes and her parents with
her difficult and uncooperative behaviour. Parental consistency would also ensure that all parties were clear about the 'rules' governing mealtimes.

Sophie's beliefs about the consequences of eating - it was felt that it would be helpful to attempt to address these beliefs as they were causing concern. Parents were encouraged and helped to talk to Sophie about why we need to eat food and where babies come from. The latter belief needed to be approached in a sensitive way.

Parents were encouraged to periodically monitor mealtime behaviour by filling in dairies. This was to remind parents and ensure constancy of techniques used also help to evaluate the usefulness of the intervention.

RESULTS

Over the course of the four months Sophie’s mother reported that both parents had employed all of the strategies suggested to them. She felt they had developed a joint and consistent approach to dealing with Sophie’s difficult behaviour. Mother reported a considerable improvement; Sophie was very rarely distressed at mealtimes and no longer hid food. The time taken to complete a meal had decreased dramatically, taking on average 15-20 minutes. The quantity and type of food that Sophie was willing to eat had also increased.

Sophie no longer believed that she would become pregnant from eating, this was reported by mother and confirmed by Sophie in our last session together. It had been explained to Sophie where babies come from; however, this had not been undertaken
by her parents, but rather another family member. Mother reported that Sophie had not recently commented that she did not want to get fat. It may have been that in no longer avoiding eating Sophie had learned that her fears were unlikely to occur.

From diaries completed towards the end of the intervention it became clear that mealtimes were no longer fraught with battles and tension. The rating mother had given to how difficult she found Sophie’s mealtime behaviour, how distressed both mother and Sophie were at these times were mainly between 0 and 1. Each parent was spending individual time with Sophie everyday that had increased to between 20 and 40 minutes. Mother reported that both parents felt more confident in dealing with Sophie and their ability to deal with difficult situations should they arise in the future.

**RECOMMENDATIONS**

The dietitian and paediatrician will continually monitor Sophie. It was recommended that the family be followed up by the psychology department in three months, to discuss any difficulties that may have occurred in the intervening period and gain reassurance and further support if needed.

**DISCUSSION AND CRITICAL REVIEW**

Although the intervention had proved relatively successful, utilising a quantitative method to evaluate outcome would have given a more reliable and objective measure of its effectiveness.
The intervention concentrated on addressing the difficult behaviour and it is possible that gains made during therapy may be only short in duration. Family therapy sessions may have been beneficial to deal with systemic issues within the family. Within the systemic approach it could be construed that the alteration in Sophie’s behaviour constituted a first order change, i.e., the behaviour changed but the system remains the same. It could be argued that it would have been more beneficial with longer lasting effects if a second order change had occurred, i.e., an alteration in behaviour that actually changes the system itself.

There was some evidence of unresolved family issues; e.g., parents appeared to experience difficulty with taking responsibility for difficult decisions. Sophie’s apparent feeling of not totally belonging to the family unit evidenced in her request to change her name was ignored by her parents in one session. It is also possible that Sophie’s eating behaviour served a function within the family, in that any conflict was diverted through her instead of being openly confronted and addressed by her parents. A systemic approach could have elucidated the family’s principal interactive patterns. It may be that the original handling of the eating problem was typical of the family’s usual way of functioning. Family therapy could help to establish a different system of functioning that would allow problems to be dealt with more effectively (Minuchin 1979). However, it was not possible for me to offer family therapy due to my level of training and the resources available within the department.

The fact that behavioural methods proved successful with this case suggests that the formulation given was reasonably accurate and that behavioural intervention is a useful approach to employ when dealing with these kinds of pre-school problems.
However, the successful outcome of the intervention could also be accounted for by variables other than the therapy received, e.g., the many changes that occurred over the course of therapy which resulted in the family feeling more settled.

This case afforded me the opportunity to develop a working understanding of behavioural methods as they relate to assessment and intervention with families experiencing common difficulties with their pre-school children. Supervision was extremely useful in making clear theory and practice links within this area, providing me with a forum to express and work through my anxieties about working with families. It helped me to meet the challenge of working with parents in a collaborative manner to encourage them to change the way they interact with their child in a way that is empowering rather than one which might undermine their confidence.
REFERENCES


CASE STUDY 3:

A PHOBIA OF CROSSING THE ROAD IN AN OLDER ADULT TREATED
WITH COGNITIVE BEHAVIOURAL THERAPY
REFERRAL

A 76 year old woman who will hereafter be referred to as Mrs. Jones was referred by her GP to the Locality Mental health Team for older adults in an Outer London Health District. The referral requested anxiety management to help Mrs. Jones overcome a “phobia” of crossing roads, which had resulted in her becoming increasingly housebound.

The referral was originally allocated to a Community Psychiatric Nurse (CPN) on the team in March 1998. The case was transferred to the current therapist when I joined the team in April 1998, after the CPN had seen Mrs. Jones on two occasions to conduct an assessment. The case was transferred to the current therapist due to the CPN’s heavy caseload, which prevented her from seeing the client on a weekly basis, which was felt necessary. The therapist was requested by the CPN and the therapist’s supervisor to provide an exposure based treatment to address the aforementioned phobia.

PROBLEM DESCRIPTION

Mrs. Jones described the main problem as a “fear of crossing the road”. This fear was of a long-standing nature and had developed some six years previously whilst she was residing in Spain. Mrs. Jones described experiencing a panic attack on a hot afternoon whilst attempting to cross a very busy road in the “town centre”. She reports that since this incident she has had difficulty crossing roads, especially large busy ones. On anticipating such an event she describes feeling “nervous”. However, Mrs. Jones reported that her fear had not interfered with her life to any great extent whilst living in Spain.
Since returning to England (due to failing health) seven months previously, Mrs. Jones reports that her fear of crossing roads has increased. This fear is now restricting her daily activities leaving her feeling dependent on her son and his wife. She finds it difficult to go out on her own due to the many roads that it is necessary to cross to carry out many daily activities. She reports feeling that she is losing her independence and feels frustrated with herself for not being able to overcome her fear. Mrs. Jones reports that she has presented for treatment at this moment in time because she is applying for a warden controlled flat. She will need to be able to cross roads to be independent when she is living on her own.

Behaviour during interview

Mrs. Jones was seen on one occasion jointly by the CPN and the therapist to conduct a ‘hand-over’ session. She appeared to have developed a strong relationship with the CPN and seemed uncomfortable with the idea of being transferred to the therapist. However, as contact increased Mrs. Jones began to engage more easily and a strong therapeutic alliance developed. She was very willing to discuss her difficulties and appeared very motivated to “face the challenges” of treatment despite being aware of the discomfort it might cause her.

Relevant Background Information and Previous Psychiatric History

Mrs. Jones describes a very happy childhood in which she had a very close relationship with her mother and helped her to look after her four younger siblings. She has been married and divorced twice, and had a son from each marriage. She went to live in Spain in her forties to start a new life and “escape” from her second...
and violent husband. Mrs. Jones described herself as a “strong willed and very independent person” who was able to make a good life for herself in Spain. She reports reluctantly returning to England but felt this was necessary due to health problems making it difficult to live far from family support. The move back to England represents many losses for Mrs. Jones including friends of 20 years, a way of life and independence. During the period that she was being assessed by the CPN, Mrs. Jones youngest son died suddenly and in unusual circumstances increasing her distress.

Health Problems

Mrs. Jones has an accumulation of health problems. She suffered a stroke in the late 1980’s, which left her with right-sided weakness. She suffers from Ischaemic heart disease and angina. She has been diagnosed as having Osteoporosis and arthritis. The above health problems have resulted in Mrs. Jones needing to use a walking stick to mobilise effectively.

Psychiatric History

Mrs. Jones reported that 40 years ago she suffered a panic attack whilst walking down a slope to a cellar at a pub where she was employed. After this she reported feeling fearful of walking on any surface with a slope on it. Mrs. Jones reported that she overcame this by “facing my fear”. She reported experiencing depression after a hysterectomy 30 years ago and describes being effectively treated with the use of antidepressants.
Assessment

During the two assessment sessions conducted by the therapist it became apparent that Mrs. Jones was suffering from a specific phobia, that of crossing roads. In addition she appeared to be experiencing some anticipatory anxiety whenever she had to leave the house to walk anywhere in which she might be required to cross a road. The Mini Mental State Examination (MMSE) was administered in order to discover if there was any cognitive impairment that would make it difficult to use Cognitive Behavioural Therapy (CBT). The Beck Depression Inventory (BDI) was also administered to ascertain if Mrs. Jones' recent bereavement had led to any depressive symptoms that might make it difficult for her to engage in the process required for CBT, (which requires much motivation and effort from the client to be effective). Mrs. Jones scored within the normal range on the BDI and the MMSE revealed no significant cognitive impairment.

THEORY

A phobia can be defined as an excessive and persistent fear of a situation or an object. The fear is regarded to be disproportional to the actual danger posed. Although it is usually recognised by the sufferer that the fear may be groundless, there is a strong desire to avoid the feared situation or object. In contrast to other fears phobias are maladaptive as they can interfere with an individual's daily activities (Butler 1989).

Behavioural theories propose that maladaptive behaviours are learned in the same manner as adaptive ones. Behavioural models argue that intense fears are acquired and maintained through the processes of classical and operant conditioning. A fear is
considered to be acquired through an association developing between a stimulus (object or situation) and a response (fear or distress). It is thought that phobias can develop at a time of high arousal or stress when fear responses are easily learned (Rachman 1977). A phobia is maintained because escaping from or avoiding the feared object generally reduces anxiety. This reduction in anxiety acts to reinforce the avoidance thus strengthening the fear (Ost & Hugdahl 1981).

Cognitive theories of phobic anxiety argue that it is primarily the individual’s cognitions in a frightening situation that will influence his or her responses to that situation, resulting in phobias being developed and maintained. It is argued that when a frightening object or situation is encountered the individual assesses its potential danger. Alongside this the individual appraises their own ability to deal with the situation in terms of ensuring their protection. Finally an estimate of the degree of danger present is assessed and a response produced (Beck et al 1985). It is thought that an individual’s tendency to hold negative beliefs about his or her ability to deal adequately with difficulties generally produces an escape response. Cognitive behavioural models of anxiety development and maintenance are generally a combination and integration of cognitive and behavioural theories.

Exposure to a phobic situation provokes an immediate anxiety response. The symptoms of which can be characterised in three domains, physiological, behavioural and subjective, subjective symptoms can consist of thoughts and/or emotions (Rachman & Hodgson 1974). Phobic individuals react to fear in the three ways described above, and these reactions prevent the symptoms from weakening and dying away. The behavioural component of avoidance is thought to be the most
forceful in maintaining the phobia. If the individual never approaches the feared situation or escapes from it each time it is encountered, he or she will never learn that the feared situation is not as dangerous as is believed.

**FORMULATION**

Mrs. Jones can be described as suffering from a simple/specific phobia of crossing roads. Which appears to have developed subsequent to experiencing a panic attack while attempting to cross a busy road in Spain some 6 years ago. Mrs. Jones reported that she had always been somewhat fearful of crossing busy roads in Spain. She commented “you take your life into your hands each time you cross the roads out there”. She had crossed this road many time previously, however, on this particular day she had been out for a long period and described feeling hot and tired. She reports that she became aware of how fast the traffic was travelling, the noise around her and suddenly felt very frightened. She reports feeling rooted to the spot momentarily, then becoming aware of many physical sensations, such as, sweating, and chest pains, shaking legs, feeling faint and a feeling of de-realism. She appears to have misinterpreted these physical sensations thinking they meant she was about to faint. These sensations were accompanied by catastrophic thoughts, e.g., “I’m going to faint, fall into the road and be killed”. She retreated from the kerb feeling very fearful and embarrassed. Subsequent to this incident Mrs. Jones developed an intense fear of crossing roads, particularly busy roads and would only attempt this task if a friend whose arm she held onto accompanied her. It appears that a vicious cycle then developed (see over).
### Situational trigger
- Hot afternoon
- Busy and noisy road

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<th>Behavioural</th>
<th>Subjective</th>
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<tr>
<td>Fatigue</td>
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<td>“I might to faint”</td>
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<tr>
<td>De-realism</td>
<td>Withdrawal from road</td>
<td>“I could fall into road”</td>
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<td>Sweating</td>
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<td>“I might be killed”</td>
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<td>Chest pains</td>
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<td>Fear</td>
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<td>Shaky legs</td>
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<td>Embarrassment</td>
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<td>Feeling faint</td>
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### Symptoms

### Reactions

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<th>Psychological</th>
<th>Behavioural</th>
<th>Subjective</th>
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<tr>
<td>Chest pains</td>
<td>Avoidance</td>
<td>“I can’t do it”</td>
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<td>Shaky legs</td>
<td>crossing with assistance</td>
<td>frustration</td>
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<td>De-realism</td>
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<td>lowered confidence</td>
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<td>Feeling faint 1989)</td>
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The above cycle did not interfere to any great extent with her daily life while she lived in Spain. This was because there were many shops and leisure facilities in the square in which she lived, resulting in her not being required to cross many (busy) roads to lead a fulfilling life. Her phobia became problematic when she returned to England. It was very difficult for Mrs. Jones to avoid crossing roads, as this was required to carry out many of the normal tasks of daily living in England. In an attempt to help her, her son and daughter-in-law who she was residing with temporarily would offer to take her wherever she needed to go. However, since both were in full-time employment it meant that Mrs. Jones was spending many hours during the day at home.
Mrs. Jones health continued to deteriorate, in addition, due to the many hours spent inactive at home and lack of exercise, Mrs. Jones gained weight. This appears to have added to her mobility difficulties as she could now only walk very short distances with the aid of a walking stick and feels unsafe to go out on her own. In this manner her fear of crossing roads was leading to her becoming somewhat housebound. Her avoidance of crossing roads was further reinforced when shortly after arriving in England she attempted to face her fear by crossing a road on her own. Unfortunately she chose a very busy road and experienced an anxiety reaction, experiencing many distressing physical symptoms, which were accompanied by catastrophic cognitions. This confirmed to Mrs. Jones that she was unable to overcome her fear, resulting in a greater loss of confidence and a stronger desire to avoid crossing roads.

The development and maintenance of Mrs. Jones phobia is consistent with the cognitive behavioural model described above, in which all three systems (physiological, behavioural and subjective) contributed to the development and maintenance of her phobia. The behaviour of significant others (friends and family) also contributed to a maintenance of Mrs. Jones phobia.

**INTERVENTION**

It has been reported that CBT is an effective intervention method when applied to older adults with anxiety problems (King & Barrowclough 1991). However, It has been argued that there are some essential prerequisites for successful treatment (Blackburn & Twaddle 1996). Mrs. Jones clearly demonstrated some of these, i.e.,
the ability to develop a therapeutic alliance, some ability to understand psychological terms and motivation to change. From this it appeared that Mrs. Jones would be an appropriate candidate for CBT.

**Treatment Plan**

The CBT approach was the intervention of choice as there is much evidence to suggest the effectiveness behavioural approaches when applied to specific phobias (Marshall 1988, Emmelkamp 1982, Ost et al 1989). Since Mrs. Jones experiences catastrophic cognitions in relation to her phobia, it seemed appropriate to incorporate a cognitive component in the treatment plan.

**Summary of Treatment**

Mrs. Jones was seen on sixteen occasions at her home over a five month period. Some time was spent developing a solid rapport with Mrs. Jones as suggested by Woods & Britton (1985) and Dicks et al (1996). Dicks et al (1996) state that CBT is a form of psychotherapy which relies greatly on the strength of the therapeutic alliance as a foundation for accomplishing treatment goals. Incorporated in this initial stage is an explanation of the approach, rationale and collaborative nature of CBT.

**Relaxation training** was undertaken to teach Mrs. Jones one way to control her physiological symptoms. This enabled Mrs. Jones to gain a sense of control over her physical reactions. Autogenic muscle relaxation was taught in preference to progressive muscle relation to take into account Mrs. Jones physical health problems.
(as suggested by Woods & Britton 1985). A relaxation tape was made for and given to Mrs. Jones for her to use in between sessions.

**Graded In-vivo exposure** was carried out. A graded hierarchy was developed and Mrs. Jones worked systematically up the hierarchy. The level of difficulty of each task was based on three factors (1) the quietness or how busy a road was, (2) the width of the road, and (3) whether or not Mrs. Jones was accompanied whilst crossing the road. Mrs. Jones also verbalised "Subjective Units of Distress" (SUDS), grading her distress on a scale of 0 to 10 during exposure which were recorded by the therapist. Exposure was mainly therapist-directed due to difficulty with completing homework in between sessions (i.e., son and daughter in law both working and not able to assist much in homework, mobility problems making it difficult for Mrs. Jones to engage in self-exposure). There is some evidence that indicates that therapist-directed exposure is markedly more effective that self-directed exposure (e.g., Ost et al 1991).

**Cognitive aspects** of the treatment programme addressed Mrs. Jones misinterpretations of the physiological sensations that occurred during an anxiety reaction. She was encouraged to generate alternative and more realistic explanations for these symptoms. She was also taught how to monitor and identify catastrophic cognitions that functioned to maintain her phobia and replace them with positive coping self-statements to be used before and during exposure.

All aspects mentioned above were discussed in each session to help Mrs. Jones assimilate the new information collected during exposure as suggested by Goldfried.
& Robins (1983) and Kendall (1984). In addition, some time was set aside each session to talk through issues of transition and the adjustments that Mrs. Jones was required to make after returning to England. These included adapting to increasing physical problems, the move from independence to semi-dependence and issues of loss.

Results

Mrs. Jones learned how to relax more effectively and was visibly able to use some of her new learned skills at “difficult moments” during exposure. Although Mrs. Jones initially had some difficulty accessing her thoughts during anxiety reactions, she was eventually able to access these negative cognitions and reported feeling quite able to replace them with more realistic alternatives. She reported that by the end of treatment she was consistently using positive coping statements to help her to deal with any anticipatory anxiety, which was accompanied by a reduction in catastrophic cognitions.

Mrs. Jones was able to complete all but the most difficult exercise of her hierarchy, which was to go out alone and cross a busy road on her own. However, she progressed from needing to hold onto someone’s arm when any crossing road, to being able to cross busy roads (using the zebra crossing) on her own and meet the therapist at the other side of the road. She was also able to cross the road while the therapist was close by but out of sight. Mrs. Jones felt that she has achieved her treatment goals despite not yet feeling able to leave the house alone and walk to a zebra crossing and go cross. However, she felt confident that in time and with more practice she would be able to do this if she wished to. Mrs. Jones SUDS ratings
reduced from typically 9-10 at the start to 1-2 by the end of treatment. This she felt was a great improvement with her anxiety at a level that she felt very able to tolerate. To enable progress to be maintained the treatment programme was ‘handed over’ to Mrs. Jones son. The CBT approach was fully explained to him, and supplemented by handouts.

After psychological intervention was completed Mrs. Jones was referred on the Occupational therapist in the team to be placed on the waiting list for an assessment when she was allocated warden controlled accommodation.

**DISCUSSION AND CRITICAL REVIEW**

A CBT approach was used to treat an elderly woman with a phobia of crossing the road. These methods succeeded in enabling the client to approach and tolerate the feared situation for prolonged periods with an accompanying reduction in her symptoms. This suggests that the formulation made was reasonable accurate. However, Mrs. Jones was seen for 16 sessions to enable her to achieve all but one of her goals. This is considerably longer than is usually expected when treating a simple phobia. It has been argued that very brief interventions can prove effective with specific and circumscribed fears (Smith et al 1990, Liddell 1994).

There probably were aspects of the treatment programme that might have been implemented more effectively. As has been previously mentioned the vast majority of the exposure was therapist-directed. The disadvantage of this is the limited practice carried out in terms of number of times exposure was engaged in and periods between each episode of exposure. Certainly the client would have attained
her goals earlier had she been able to complete her homework on a regular basis. As it was, she had the opportunity to practice only eight times in between sessions due to physical disability and her family not having the time to accompany her on her homework tasks.

In addition, when she did manage to complete a homework task she was not required to monitor her cognitions (usually recorded in written form), due to weakness in her dominant hand. This may have delayed her progress in this area. In hindsight this difficulty could have been overcome with some creativity from the therapist. For example, Mrs. Jones could have been instructed to carry out self-monitoring using audiotape. This is just one of the adaptations to therapy suggested by Woods & Britton (1986) to make therapy more effective with older adults.

This case illustrates some of the complexities involved in working with older adults even when treatment focuses on a circumscribed problem. Mrs. Jones had physical health difficulties, she was going through a difficult transition period, whilst trying to adjust and come to terms with many life events and losses. The effect of these factors had to be considered in terms of their possible influence on motivation and ability to engage with and carry out the intervention. The supportive counselling that was offered to Mrs. Jones to help her think about the meaning of some of her recent experiences; alongside allowing her time and space to express her feeling about difficult issues was really an adjunct to CBT. She may have benefited from a more structured form of intervention around the above issues, such as life review therapy.
The difference in age between the therapist and client might have posed a difficulty at the beginning of therapy, which slowed the process, somewhat. Indeed in the early stages of treatment the client directly questioned the therapist's qualifications and experience and commented that she was younger than her own granddaughter. This potentially could have damaged the therapeutic alliance had the therapist responded in a defensive manner. As it was the discussions around these issues appeared to serve to strengthen the therapeutic alliance.

The success of this case supports King & Barrowclough (1991) assertions that CBT can be an effective intervention with older adults suffering from anxiety. However, more research is required to examine the nature of anxiety in older adults, and the most effective treatment approaches. There has been much research into affective disorders in older adults; however, the vast bulk of it concentrates on depression (Woods & Britton 1985). Therefore more research is required that focuses on anxiety problems in older adults.
REFERENCES


CASE STUDY 4:

PSYCHOTHERAPY EXPLORING LOSS WITH A WOMAN WITH MILD LEARNING DISABILITIES
**REASON FOR REFERRAL**

K a 22 year old woman with cerebral palsy and mild learning disabilities was referred by her social worker to an Inner London Multi-Disciplinary Community Health Team (MDCHT) for people with learning disabilities. The referral requested assistance from psychology for K and her mother Mrs S. K was reported as having angry outbursts at home in which she could become verbally and physically aggressive. Aggression was described as directed mainly towards her mother.

**Background to referral**

Three months previously K’s GP referred the family to social services requesting the provision of respite care for K. The GP felt that Mrs. S was suffering from depression following the death of her mother some five months previously. He expressed doubts about Mrs. S’s ability to continue to care for K long-term unless K was given regular respite care. K had received respite care six weeks before the referral to the MDCHT; however, K’s angry outbursts had increased in frequency since returning home. Therefore, social services had referred the case onto the MDCHT for advice and support regarding K’s aggression towards her mother.

**PROBLEM DESCRIPTION AND ASSESSMENT**

**Behaviour and appearance**

One of the four clinical psychologists from the MDCHT and the current therapist visited Mrs. S and K at their home to conduct an initial assessment. Mr. S did not attend the interview despite being at home at the time. Mrs. S is in her early fifties.
with a smart well-maintained appearance. She spoke openly and forcefully during the interview about the problems being experienced. On one occasion during the interview K asked her mother to help take off her cardigan. Mrs. S appeared annoyed but after initially telling K she could do it herself, she did as her daughter had asked.

K presented as a tall overweight young woman whose hair and clothes were untidy. She appeared very shy and tended to physically try to hide behind her mother. She found it difficult to respond verbally even when she was asked a direct question and appeared to look to her mother for help. K spoke clearly on one occasion only; this was when her mother mentioned the death of K’s maternal grandmother. In addition to the desire for K to be looked after in a group home should anything happen to Mr. and Mrs. S. At this point K was visibly distressed saying to her mother “I don’t want to talk about it”.

Mrs. S described the main problem as her daughter being very reliant on, and needing a high level of care and attention from herself. She reported that K is “unwilling to become more independent even with simple tasks she is very capable of carrying out herself”. K is likely to become aggressive if she is told “no”. Typically K would request her mother’s assistance with a basic self-care task such as taking a bath, brushing her teeth or help with toileting. If Mrs. S refused, this could lead to K becoming verbally and physically aggressive. Mrs. S also reported that difficulties arose due to K’s refusal to help with household tasks despite being “old enough to, and very able to help”. This can cause frustration and anger for both mother and daughter. Occasionally when K hits out at her mother, Mrs. S retaliates. Mrs. S became tearful when speaking about hitting back at her daughter. Mrs. S
reported that K had always responded with anger at refusal of requests, but over the last month angry outbursts had become more frequent. Mrs. S reported that aggression occurred only in the family home, and she was the only target of K’s aggression.

Mrs. S reported that over the past few months she has been finding it increasingly difficult to cope with the high demands placed upon her by her daughter. Since her return from respite care both parents have tried to encourage K to do more for herself. Mr. and Mrs. S were told by staff at the respite home that whilst there K had carried out most of her personal self-care needs and also helped with chores around the home. Mrs. S reported that instead of showing an increase in independence, K seemed to become more dependent since her return from respite. Mrs. S reported that both parents were concerned about K’s future care and wished her to be more independent so that she would be able cope living in a small group home with support “when the time came”.

RELEVANT BACKGROUND INFORMATION

K is the younger of Mr. and Mrs. S’s two daughters and lives in the family home with her parents. Her sister who is two years older than K lives away from the family home. Mr. S suffers from agoraphobia with panic attacks and spends much of his time at home.

Mrs. S had an uneventful pregnancy and K was born full-term. When K was 13 months old cerebral palsy was diagnosed. K had a left-sided weakness and a deformed leg, she had a number of operations before she was 11 years old and was
therefore separated from her family. When K was three and a half years old she was diagnosed as having learning disabilities. This came as a shock to her parents. Mrs. S reported that the family had a great deal of difficulty coming to terms with the fact that K was "mentally handicapped" and recalled her anger that this had not been diagnosed at the same time as the cerebral palsy. As K was growing up Mrs. S found it hard to refuse her daughter anything she wanted. Due to her being both physically and mentally handicapped, Mrs. S felt it was her duty to make K's life as easy as possible.

Many changes have occurred for K over the past 12 months. She has recently started a course at one of the local colleges. Eight months ago K's maternal grandmother died. Since this time Mrs. S has found it increasingly difficult to cope with the high demands placed on her by her daughter, therefore, she has been encouraging K to become more independent. Recently Mrs. S requested respite care for K so that she could have a break. The last time K had respite was nine years previously when she was 13 years old.

**THEORY**

From childhood people with learning disabilities face a number of damaging and unpleasant life experiences. These experiences can be seen as a product of society's beliefs and behaviours towards people with learning disabilities. These experiences include rejection, physical segregation, lack of relationships, lack of freedom and control and the awareness of being a burden to others (Jean Vanier in Waitman & Conboy-Hill 1992). Szivos & Griffiths (1992) argue that people with learning disabilities are stigmatised, and can become aware of the stigma. This occurs when
individuals become aware that they are different. This difference can be viewed as the discrepancy between actual identity and what is seen as “normal”. When this occurs individuals experience the emotional stages of loss. People with learning disabilities may have to cope with multiple separations and losses over their life span.

Psychodynamic theorists such as Sinason (1992) and Bicknell (1983) emphasise the importance of loss in disability both for the individual and families with a disabled member. The very birth of a child with disabilities can be perceived as a loss, as families struggle with the ‘loss of the perfect child’ they had expected. This may be the first of many losses that have to be processed and resolved. Bicknell (1983) describes parents’ common reaction to the birth of a disabled child as similar to the bereavement process or grief. Grief can be maladaptive if a parent becomes fixated at this stage and rejection or over-protection may occur. However, it is more common for ambivalence to occur. This is a mixture of over-protection and rejection, the parent and/or the child may or may not be consciously aware of the ambivalence (Bicknell 1983).

Sinason (1992) argues that life is full of losses. She states “from the moment of birth we are dispossessed of our first country, the womb” (p86). She states that each new stage in normal development involves separation, which can be perceived as loss. Possibly for someone with learning disabilities these separations and losses are more profound. There can be disruptions to the smooth transition from one stage of development to the next. Successful negotiation of developmental stages for all individuals leads to an increasing sense of autonomy. Due to the fact that people
with learning disabilities often need to be tended to physically, emotionally and socially a sense of autonomy may be difficult for individuals to achieve and for carers to enable (Sinason 1992).

The family can be seen as progressing through different transitional stages which need to be negotiated by all family members, as proposed by family life cycle theorists (Catrer & McGoldrick 1988). When a family contains an individual with learning disabilities, the normal sequence of life cycle transitions may be altered or crisis ensues at particular life cycle stages. For example, a young adult’s difficulty moving from adolescence into adulthood causes a crisis in the family at the stage when non disabled young people would usually be leaving home (Goldberg et al 1995). This usually involves loss, for parents with learning disabled offspring the loss can be perceived as loss of expected freedom, which would occur when non-disabled offspring leave home. However, this time can remind parents of previous losses, if these are unresolved they will cause a reactivation of the pain associated with that loss (Bicknell 1983). Psychodynamic theorists such as Sinason (1992) argue that repressed losses re-emerge sooner or later and subsequently increase the vulnerability of the individual, therefore resolution of loss is of utmost importance.

FORMULATION
The shock of finding out that her daughter had a learning disability in addition to a physical disability was very difficult for Mrs S to accept. It is possible that this news reactivated the feelings of ‘loss of the perfect child’. It is possible that with this new information, the grieving process became fixated (Bicknell 1983). Mrs S does seem to have overprotected K to some degree, giving in to her wants wherever possible
and taking responsibility for her personal self-care needs longer than was necessary. However, in addition to over-protection, it is possible that Mrs S also experienced rejecting feelings towards her daughter. It could be argued that Mrs S's attempts to maintain control over her internal feelings of rejection towards her disabled child has resulted in an inability for her to mourn the 'loss of the perfect child'. The lack of resolution of these feelings could have been powerfully reactivated by the loss of her own mother. As Freud (1909) commented, the thing which is warded off finds its way into the very means which are used for warding it off. Unbearable feelings are often displayed in this way.

Following the impact of her mother's death it is possible that Mrs. S has become aware of her own mortality. This may have made her own death a very real and urgent issue and her need for her daughter to be independent is borne out of her wish for her daughter to be secure when she is no longer there to look after her. However, it is very likely that she has not sufficiently prepared her daughter for autonomy by not allowing her to take care of her basic needs. This will make the idea of independence very frightening for K who may not understand and equate requests to look after herself with a loss of love or even the impending loss (death) of her parents.

It is not clear how the death of her grandmother has impacted on K. However, it is very likely that she is aware of the distress within the family. It is likely that since her grandmother's death her own mother has not been as available to her as before. Certainly if her mother is depressed as the GP stated, it would be difficult for her to be as responsive to K's needs. K's anger and resistance towards becoming more
independent and therefore negotiating her next stage of development from adolescence to adulthood may be seen as a defence in an attempt to suppress feelings of loss. She is experiencing the potential loss of her nurturing mother, loss of the relative safety and protection of childhood and loss of the illusion of 'normality' as she is forced to face up to the reality of her learning disability. This perhaps is made more potent by the fact that she has recently started a course at college and is for the first time mixing with non-disabled adults on a regular basis. This will make the reality of her difference and learning disability more difficult to deny. This can be a painful reality that is defended against (Szivos & Griffiths 1992).

It is not surprising that K’s dependence on her mother and aggression at requests to be more independent has increased since her stay in respite care. This separation after nine years is likely to have been perceived by K as a rejection by her parents, and feelings of abandonment may have caused her great distress. Her behaviour could be conceptualised as an attempt to escape back to the security childhood. If K equates being looked after by her mother with being cared for and loved, she will be resistant to begin to negotiate a stage of development which is possibly very frightening and for which she is ill equipped. K’s increase in aggression to her mother could be viewed as one way that she communicates her distress (Lovett 1987).

Therefore, the current difficulties can be conceptualised as K’s way of coping with the potential losses she is experiencing. Her mother is less available to her emotionally and physically and she attempts to regain her mother’s love by regressing to an earlier stage of development in which she felt loved, protected and
secure. However, given that her mother is also dealing with feelings of loss, her strategy to obtain what she needs from her mother will be unsuccessful. Furthermore, it is likely to increase the likelihood of the consequences that K most fears, that her mother will feel unable to cope and think seriously about a residential placement for K.

**INTERVENTION**

It was felt that both mother and daughter could benefit from support. Mrs. S was offered sessions with one of the qualified psychologists to provide support around managing K's behaviour. However, what will be presented here is a summary of the current therapist's input with K.

K was offered 12 weekly sessions of individual therapy, each session lasted 60 minutes. The purpose of these sessions was to provide a safe space for K to begin the process of exploring her feelings around difficult issues such as loss. It was hoped that by providing an opportunity for K to talk openly about her feelings this might facilitate her to be more able to express difficulties verbally reducing the need to communicate through aggression. One of the first steps in the process was to help K to become aware of and recognise different types of emotion felt and expressed both in herself and others. The techniques used were adapted to K’s cognitive level and various mediums were used to facilitate the recognition of and expressions of emotions, for example colour photo-cards (Hurley 1989).
RESULTS

K attended all 12 sessions and always appeared keen to join the therapist in the interview room. Initially K would only talk about positive feelings such as happy and excited. She found it very difficult to even look at photos depicting people showing strong emotions such as anger or sadness. Over time she found this easier and began to talk about her own feelings. However, it was only in the last three sessions that K felt safe enough to move away from talking about things that made her happy to talking about what made her sad and angry. Mrs. S reported that there was a reduction in angry episodes at home and K was hitting out much less. She was also beginning to take responsibility for some of her personal self-care needs. This however was very limited.

At the end of therapy it was recommended that K be offered longer-term psychotherapy to build on and continue the process begun over the 12 sessions. It was clear that K could use the sessions appropriately and appeared to be gaining some benefits from having time and space to think and talk about difficult feelings and issues.

DISCUSSION AND CRITICAL REVIEW

The results suggest that the intervention was to some degree successful. However, it is unclear as to whether the reduction in frequency of aggression could be attributed to the sessions K received. It is possible that having the opportunity to speak about difficulties and express her feelings openly reduced the need for her to ‘act them out’. Lovett (1987) suggests that difficult behaviour such as aggression can be seen as a means of communicating distress when no other means appear available.
However, it is equally possible that the improvements made were a result of the support and advice given to Mrs. S around better management of difficult behaviours.

The process of engagement can take longer with people with learning disabilities (Sinason 1992). Therefore relatively brief interventions such as the one described here may fall short of addressing the pertinent issues due to time constraints. K did appear to have some difficulty initially engaging in the therapeutic process. Although she was always keen to join the therapist in the interview room and could tolerate 60-minute sessions, she did have difficulty talking about her feelings. Emotions were only really explored in relation to K and her difficulties at home in the last three sessions. In these sessions K spoke about “sometimes feeling angry” in addition to speaking about her grandmother and “being sad”.

As suggested by Sinason (1992) and Bicknell (1983) the issue of loss is very pertinent to people with learning disabilities and their families. It could be argued that although the therapy gave K the positive experience of being able to talk about her feelings and have them validated, it was also another experience of potential loss for K. After engaging with and beginning to trust the therapist enough to talk about painful feelings the therapist leaves. Perhaps it would have been more ethical for one of four permanent psychologists to work with K on a longer-term basis.

The formulation suggested that loss was a current issue for both K and her mother and presumably the whole family. Bicknell (1983) argues that the issue of recurrent loss needs to be negotiated and addressed by each member of the family. Given that
K's grandmother's death appears to be the factor that precipitated some of the current difficulties, a systemic approach may have been beneficial to help the whole family to deal with, and come to terms with this loss. Work based on the family life cycle theory (Carter & McGoldrick 1988), may have been useful to help the family to negotiate the transitional stage it appeared to be facing with the possibility of K becoming more independent. However, given Mr. S's difficulties with agoraphobia it is possible that this would have been difficult to set up.

It is difficult to evaluate the outcome of psychotherapy with people with learning disabilities. However, the subjective impression of the therapist was that the client was better able to recognise her own and other people's feelings. She was also better at expressing some of her own feelings. This suggests that psychotherapy can be beneficial for people with learning disabilities. However, given the very real issues of loss and the time it can take for an individual with learning disabilities to engage in therapy, it appears that longer-term work would be more beneficial and possibly more ethical with this client group.
REFERENCES


SERVICE RELATED RESEARCH:

THE AUDIT OF REFERRALS TO A MULTI-DISCIPLINARY COMMUNITY HEALTH TEAM FOR PEOPLE WITH LEARNING DISABILITIES
INTRODUCTION
This project audited the referrals to a Multi-Disciplinary Community Health Team (MDCHT) for people with learning disabilities serving a multi-ethnic inner London borough. All the referrals to the service over a three-month period were examined to provide the service with a clearer picture and documented evidence of the types of referrals received.

Prevalence
There is no precise information nationally available regarding the prevalence of learning disabilities. This is partly due to the 1991 census not specifically collecting data about people with learning disabilities. However, it has been estimated that in an average district of 250,000, 5000 people are likely to have learning disabilities; of these 750 - 1000 will have a disability of a severity to require significant assistance with the tasks of daily life (Nadrishaw 1997). The adjusted 1991 census population figures for the borough being studied was 224,000; from this we can estimate between 672 - 896 people will have learning disabilities requiring some form assistance. This is likely to be an under estimation due to the high number of individuals who moved back to the borough during the closure of long-stay hospitals between 1992 and 1998.

Normalisation and Community Care
The move away from large-scale institutions towards a more comprehensive service delivery, which is community based, was influenced by the normalisation principle. This argues that people with learning disabilities should have conditions of everyday life as close as possible to the patterns and norms of mainstream society. They
should also be entitled to the same human rights available to others in society (Rapley & Baldwin 1995; Wolfensberger 1980). However, to achieve this they often require long-term support from specialist health, education and social services.

The Need for Multi-Disciplinary Teams
People with learning disabilities are not a homogenous group but represent a wide spectrum of abilities, clinical manifestations and behaviour. As such, a multi-agency and multi-disciplinary approach is required to support and assist community living for this group (Nadrishaw 1997). Hollins (1985) argues that it is not desirable for one profession to work in isolation with this group due to the complex range of health, education and social problems. In addition, it is thought that any one profession is not adequately equipped to deal with all the needs of this client group on its own. In multi-disciplinary teams, the skills of many professionals can be pooled to produce a better and more comprehensive service for people with learning disabilities than can be provided by a single professional working alone. There is also less risk of professional 'burn out' (Hollins 1985).

Sexuality and People with Learning Disabilities
Since the inception of normalisation, there has been a general growth in the desire to identify and promote the rights previously denied to people with learning disabilities, for example, the right to express their sexuality (Craft 1987). This has also led to increased attention to the issue of sexual abuse in this group. Estimates of prevalence are still sparse and imprecise, with no national data available. (Brown and Turk 1992; Brook 1985). Some studies have estimated a prevalence rate as low
as 4-5% (Baker 1985), whilst others estimate rates as high as 1 in 3 and 1 in 4 (Chamberlain 1984; Brown 1991).

It is also becoming increasingly recognised that often people with learning disabilities express themselves sexually in socially inappropriate ways; for example they might masturbate publicly. However, it has been argued that it is unrealistic for society to demand that individuals who have never been taught, or had the opportunity to develop sexually in a natural environment, behave in a sexually responsible manner (Krempton 1978; Mitchell 1987). The above issues and difficulties regarding sexuality leaves patients and carers at a loss of how to deal with and redirect such behaviour into more socially acceptable ones. This is a situation that might lead to a referral to a specialist community team for advice and support (Burns 1993).

Some health authorities have argued that a high proportion of community workers caseloads involves people who experience major problems in expressing their sexuality in a sociably acceptable and appropriate manner (Link 1996). The MDCHT in which the present study was conducted has recently made a joint bid for finance to fund a post for a specialist worker in sexual health for people with learning disabilities. It was argued that an increasing number of referrals received by the team involved individuals experiencing sexual difficulties. Moreover, it was estimated that approximately 25% of cases held by team members involved someone with sexuality/sexual difficulties.
This study is an audit of referrals made to a MDCHT for people with learning disabilities in an Inner London borough and aims to:

1. Examine the types of referrals received by the team, who takes the referral on and the types of intervention offered. An additional interest was to discover if the referrals reflect the multiple problems highlighted in the literature (e.g., Nadrishaw 1997; Hollins 1985).

2. Investigate the frequency and type of sexuality/sexual difficulties being experienced by clients presenting to the team. It is expected that a high proportion (at least 25%) of referrals with some sexuality difficulty will have been received by the team over the period examined.

METHOD

The MDCHT examined in this study is a specialist community health service for people with learning disabilities who are 16 years or older. The team works with individuals, their relatives and carers, in addition to offering advice and support to other professionals.

Details of all referrals made to the community health team were collated for the months of July, August and September 1997. Information was obtained from the trust database and patient files. The following patient and service characteristics were examined.

- Age, gender, ethnicity
- Source of referral
- Type of accommodation
- Reason for referral
- Information given on referrals
- Assessment profile
- Response time for assessment
- The professional the referral was allocated to following assessment
- The type of intervention offered
- Numbers and type of sexual problems being experienced.

Referrals are allocated for initial assessment at weekly referral meetings, which are attended by one member of each profession. The referrals are discussed, and the two disciplines thought most likely to be involved with the case take on the referral to complete an initial assessment interview. Referrals are seen within a four-week (20 working days) period after the receipt of the referral. Assessment interviews are carried out using standard semi-structured assessment forms.

RESULTS

During the period from 1 July 1997 to 30 September 1997, 56 referrals were made to the team by various agencies/professionals. In addition, 38 inter-team referrals were made; therefore 94 referrals were actioned over the target three-month period. Of the 56 referrals made by outside agencies, five were inappropriate as they did not meet the criteria for team involvement, and were therefore not considered for assessment.
Of the 56 outside referrals 29 (51.0%) had received prior input from the team, therefore 49% were new referrals. Two clients were referred twice within the three-month period for separate episodes of care from different professions within the team.

For the remainder of this report the 51 appropriate referrals made to the team by outside agencies will be referred to as the new referrals for this period (unless otherwise stated), despite a large proportion of these being previously known to the team. Due to the limitations of space, inter team referrals will not be reported here.

**Age and Gender**

Of the original (56) referrals an equal proportion of males and females were referred. Ages ranged from 14 years to 82 years with a mean age of 35 years old. Table 1 shows the age and gender of new referrals.

**Table 1: Age and gender of clients**

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Women</th>
<th>Men</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>11-20</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>21-30</td>
<td>7</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>31-40</td>
<td>9</td>
<td>9</td>
<td>18</td>
</tr>
<tr>
<td>41-50</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>51-60</td>
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<td>0</td>
<td>2</td>
</tr>
<tr>
<td>61-70</td>
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<td>1</td>
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<tr>
<td>Total</td>
<td>28</td>
<td>28</td>
<td>56</td>
</tr>
</tbody>
</table>
Ethnicity

To enable comparisons to be made the trust figures for different ethnic groups were merged together to mirror population figures for the borough.

Table 2: Ethnic origin of clients and the borough’s residents

<table>
<thead>
<tr>
<th>Ethnic Origin</th>
<th>% of referrals</th>
<th>% of population</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
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<td>58</td>
</tr>
<tr>
<td>Black Caribbean</td>
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<td>7</td>
</tr>
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<td>Black African</td>
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<td>6</td>
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<tr>
<td>Black other</td>
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<tr>
<td>Indian</td>
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</tr>
<tr>
<td>Pakistani</td>
<td>9.8</td>
<td>6</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>2.0</td>
<td>4</td>
</tr>
<tr>
<td>Asian other</td>
<td>0</td>
<td>3.1</td>
</tr>
<tr>
<td>Chinese</td>
<td>0</td>
<td>0.8</td>
</tr>
<tr>
<td>Other ethnic groups</td>
<td>3.9</td>
<td>3</td>
</tr>
<tr>
<td>No data</td>
<td>23.5</td>
<td></td>
</tr>
</tbody>
</table>

Type of Accommodation

Many people recently moved back into the community from long stay hospitals and were resettled in group homes. A large proportion of individuals referred to the team live in residential care (33.9%). However, table 3 shows that the majority live in private/family homes (58.8%).

Table 3: Types of Accommodation

<table>
<thead>
<tr>
<th>Accommodation</th>
<th>Number of clients</th>
<th>Percentage of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family home</td>
<td>25</td>
<td>44.6</td>
</tr>
<tr>
<td>Own flat/house</td>
<td>8</td>
<td>14.2</td>
</tr>
<tr>
<td>Residential/group home</td>
<td>19</td>
<td>33.9</td>
</tr>
<tr>
<td>Flat-assisted living scheme</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>3.6</td>
</tr>
</tbody>
</table>
Source of Referrals

Over the three-month period, referrals were received from various sources and table 4 gives details.

Table 4: Source of referrals frequency and percentage of total referrals

<table>
<thead>
<tr>
<th>Source of Referral</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residential staff</td>
<td>15</td>
<td>26.8</td>
</tr>
<tr>
<td>Social Services</td>
<td>15</td>
<td>26.8</td>
</tr>
<tr>
<td>G.P.</td>
<td>6</td>
<td>10.7</td>
</tr>
<tr>
<td>Consultant, psychiatric ward NHS</td>
<td>5</td>
<td>8.9</td>
</tr>
<tr>
<td>Other NHS professional</td>
<td>5</td>
<td>8.9</td>
</tr>
<tr>
<td>Relative</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>Community Mental Health Team</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>Wheelchair Services NHS</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>Probation Service</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>School</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Self referral</td>
<td>1</td>
<td>1.8</td>
</tr>
</tbody>
</table>

The largest source of referrals to the team were residential staff and social services, each making 15 referrals, accounting for 53.6% of all referrals.

Reason for Referral

Table 5 illustrates the variety of reasons for which people were referred. The most common being 'physical disabilities/mobility problems' which accounted for 33% of all new referrals. Many referrals (41.5%) requested input from the team for more than one problem.
Table 5: Reasons for referral, their frequency and percentage

<table>
<thead>
<tr>
<th>Reason for referral</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical disability and mobility problems</td>
<td>17</td>
<td>33.3</td>
</tr>
<tr>
<td>Behavioural problems</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>Communication difficulties</td>
<td>8</td>
<td>15.7</td>
</tr>
<tr>
<td>Monitoring of Mental Health/advice</td>
<td>8</td>
<td>15.7</td>
</tr>
<tr>
<td>Request for equipment</td>
<td>7</td>
<td>13.7</td>
</tr>
<tr>
<td>Deficits in independence/social skills</td>
<td>7</td>
<td>13.7</td>
</tr>
<tr>
<td>Request/review of medication</td>
<td>6</td>
<td>11.8</td>
</tr>
<tr>
<td>Request to transfer care to community team</td>
<td>6</td>
<td>11.8</td>
</tr>
<tr>
<td>Management/advice regarding sexual problems</td>
<td>4</td>
<td>7.8</td>
</tr>
<tr>
<td>Support to access community services</td>
<td>3</td>
<td>5.9</td>
</tr>
<tr>
<td>Emotional/adjustment difficulties</td>
<td>3</td>
<td>5.9</td>
</tr>
<tr>
<td>Assessment of needs</td>
<td>3</td>
<td>5.9</td>
</tr>
<tr>
<td>Staff consultation/training</td>
<td>2</td>
<td>3.9</td>
</tr>
<tr>
<td>Assessment/advice regarding future care</td>
<td>2</td>
<td>3.9</td>
</tr>
<tr>
<td>Anxiety and/or depression</td>
<td>1</td>
<td>1.9</td>
</tr>
</tbody>
</table>

47% of the new referrals were either addressed to, or requested input from a particular profession. For example, 19% requested input from the consultant psychiatrist and 53% of referrals were addressed to the team.

Professionals and carers referring an individual to the team requested with the highest frequency were ‘consultations/staff support’ and ‘for the team to assume responsibility for a client’s care’; these accounted for 31.4 % of the services requested. A large number of referrals (19.6) requested 2 or more services for the client.
Table 6: Information provided by referrers frequency of the different types of information given and percentage

<table>
<thead>
<tr>
<th>Information provided</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal History</td>
<td>25</td>
<td>49.0</td>
</tr>
<tr>
<td>Detailed History of presenting problem</td>
<td>25</td>
<td>49.0</td>
</tr>
<tr>
<td>Social Situation</td>
<td>24</td>
<td>47.0</td>
</tr>
<tr>
<td>History of Physical Health</td>
<td>21</td>
<td>41.2</td>
</tr>
<tr>
<td>Detailed information Regarding Specific Concern of Carer/Professional</td>
<td>16</td>
<td>31.4</td>
</tr>
<tr>
<td>Medication</td>
<td>15</td>
<td>29.4</td>
</tr>
<tr>
<td>Mental health Problems</td>
<td>12</td>
<td>23.5</td>
</tr>
<tr>
<td>Behavioural Problem</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>Emotional/Adjustment problems</td>
<td>9</td>
<td>17.6</td>
</tr>
</tbody>
</table>

Referrals varied according to the quantity of information provided; however the majority of referrers (56.7%) provided three or more pieces of information about the client being referred. A large number (27.4%) provided 5 or more pieces of information; moreover, some also sent letters and reports of previous work and issues for the client being referred.

Of 51 new referrals, 15 had received a previous assessment from the team within the past 24 months, therefore a new assessment was deemed unnecessary. Therefore, figures here represent the 36 referrals that received assessments.

Response Time Following Referral

The response time over the three-month period varied greatly ranging from 1 day to 108 days. However, the majority (72.2%) was responded to within 20 working days of referral receipt. In addition, 44.4 % were seen within working 10 days (see table 7).
Table 7: Response times from referral to first assessment interview, their frequency and percentage.

<table>
<thead>
<tr>
<th>Response Time (in working days)</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5</td>
<td>9</td>
<td>25.0</td>
</tr>
<tr>
<td>6-10</td>
<td>7</td>
<td>19.4</td>
</tr>
<tr>
<td>11-15</td>
<td>6</td>
<td>16.7</td>
</tr>
<tr>
<td>16-20</td>
<td>4</td>
<td>11.1</td>
</tr>
<tr>
<td>21-25</td>
<td>1</td>
<td>2.8</td>
</tr>
<tr>
<td>26-30</td>
<td>2</td>
<td>5.6</td>
</tr>
<tr>
<td>31-35</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>36-40</td>
<td>2</td>
<td>5.6</td>
</tr>
<tr>
<td>41-45</td>
<td>2</td>
<td>5.6</td>
</tr>
<tr>
<td>46-50</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>51-55</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>56-60</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>61+</td>
<td>3</td>
<td>8.2</td>
</tr>
</tbody>
</table>

Table 8: Referrals assessed by different professions, number and percentage retained by assessor for intervention

<table>
<thead>
<tr>
<th>Profession conducting assessment</th>
<th>Number of assessments</th>
<th>Percentage</th>
<th>Number of referrals retained</th>
<th>Percentage retained for intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatry</td>
<td>17</td>
<td>47.2</td>
<td>17</td>
<td>100</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>9</td>
<td>25</td>
<td>8</td>
<td>88.9</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>7</td>
<td>19.4</td>
<td>6</td>
<td>85.7</td>
</tr>
<tr>
<td>Speech and language therapy</td>
<td>3</td>
<td>8.3</td>
<td>3</td>
<td>100</td>
</tr>
<tr>
<td>Psychology</td>
<td>3</td>
<td>8.3</td>
<td>3</td>
<td>100</td>
</tr>
<tr>
<td>Community nursing</td>
<td>1</td>
<td>2.8</td>
<td>1</td>
<td>100</td>
</tr>
</tbody>
</table>

The consultant psychiatrist assessed the highest proportion of referrals over the three-month period, and retained all for intervention. Of the 36 assessments, 83.3% were conducted by a single member of the team. This was despite the policy for referrals to be jointly assessed.
The team consisted of different numbers of permanent staff in the period being examined. Some were full time while others were part time; in addition, some were qualified whilst others were unqualified. Table 9 shows the discipline members in post.

Table 9: Discipline members in post between July and September 1997

<table>
<thead>
<tr>
<th>Discipline</th>
<th>No. of members in post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community nursing</td>
<td>7.0</td>
</tr>
<tr>
<td>Clinical psychology</td>
<td>6.2</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>4.0</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>4.0</td>
</tr>
<tr>
<td>Speech and language</td>
<td>2.6</td>
</tr>
<tr>
<td>Consultant psychiatry</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>24.8</td>
</tr>
</tbody>
</table>

Assessment Profiles

The assessment profiles fell into 9 categories (see table 10). The vast majority of clients were assessed as having more than one difficulty requiring intervention (80.4%). The categories most frequently found were ‘physical/mobility problems’ and ‘behavioural problems’; these were problems for 31.4% and 29.4% respectively of people referred.
Table 10: Assessment profiles of the referrals, frequency and percentage

<table>
<thead>
<tr>
<th>Assessment Profiles</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical/mobility</td>
<td>16</td>
<td>31.4</td>
</tr>
<tr>
<td>Behavioural problem</td>
<td>15</td>
<td>29.4</td>
</tr>
<tr>
<td>Deficit in social/independence skills</td>
<td>13</td>
<td>25.5</td>
</tr>
<tr>
<td>Anxiety and/or depression</td>
<td>12</td>
<td>23.5</td>
</tr>
<tr>
<td>Communication difficulties</td>
<td>11</td>
<td>21.6</td>
</tr>
<tr>
<td>Emotional/Adjustment difficulties</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>Health difficulties and medication</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>Carer Support Required</td>
<td>8</td>
<td>15.7</td>
</tr>
<tr>
<td>Staff Support/Consultation required</td>
<td>6</td>
<td>11.8</td>
</tr>
</tbody>
</table>

**Intervention**

The figures in this section represent all 51 of the appropriate referrals made to the team over the 3-month period. The interventions offered fell into 13 categories (see table 11). Various types of intervention were offered to clients, their carers and professionals. The intervention offered with the highest frequency (27.5%) was ‘psychiatric assessment, support and follow-up’. The intervention with the lowest frequency was ‘monitoring of a physical health condition’ (3.9%). A number of clients were offered more than one type of intervention (19.6%), with 14.6% being offered 3 or more. However 5 clients (9.8%) were placed on the waiting lists of different professions.
Table 11: Intervention offered

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatric assessment/support/follow-up</td>
<td>14</td>
<td>27.5</td>
</tr>
<tr>
<td>Communication-skills assessment/development training</td>
<td>12</td>
<td>23.5</td>
</tr>
<tr>
<td>Social / independence skills-assessment / development training</td>
<td>10</td>
<td>19.6</td>
</tr>
<tr>
<td>Physical assessment/remedial physiotherapy</td>
<td>9</td>
<td>17.6</td>
</tr>
<tr>
<td>Staff consultation/training</td>
<td>7</td>
<td>13.7</td>
</tr>
<tr>
<td>Medication monitoring/review</td>
<td>6</td>
<td>11.8</td>
</tr>
<tr>
<td>Support to access community facilities</td>
<td>5</td>
<td>9.8</td>
</tr>
<tr>
<td>Assessment, Equipment/mobility aid</td>
<td>5</td>
<td>9.8</td>
</tr>
<tr>
<td>Psychological testing</td>
<td>4</td>
<td>7.8</td>
</tr>
<tr>
<td>Advice/support to carers</td>
<td>4</td>
<td>7.8</td>
</tr>
<tr>
<td>Individual therapy/counselling</td>
<td>3</td>
<td>5.9</td>
</tr>
<tr>
<td>Monitoring of physical health conditions</td>
<td>2</td>
<td>3.9</td>
</tr>
<tr>
<td>Waiting list</td>
<td>5</td>
<td>9.8</td>
</tr>
</tbody>
</table>

Sexuality/Sexual difficulties

Over the 3-month period, 13 referrals involving the presence of a difficulty in sexual expression were made to the team. This represents 25.5% of referrals within this period. Table 12 illustrates the types of sexuality/sexual difficulty being experienced.

Table 12: Sexuality/sexual difficulty experienced by clients frequency and percentage

<table>
<thead>
<tr>
<th>Sexuality difficulties</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexually inappropriate behaviour</td>
<td>10</td>
<td>19.6</td>
</tr>
<tr>
<td>Victim of sexual abuse</td>
<td>2*</td>
<td>3.9</td>
</tr>
<tr>
<td>Perpetrator of sexual abuse</td>
<td>2*</td>
<td>3.9</td>
</tr>
<tr>
<td>Sexually exploited</td>
<td>1</td>
<td>1.7</td>
</tr>
</tbody>
</table>
* Represents in the above table two individuals referred to the team and not four, both adults who were categorised as perpetrators of sexual abuse reported previously being abused themselves as children, therefore, they are recorded in both categories.

DISCUSSION

The quality of the referrals made to the team was generally of a good standard, containing detailed information. Over 50% (56.7%) provided three or more pieces of information, such as, family, medical and psychiatric history. This high standard facilitated appropriate allocation to the different disciplines for assessment and intervention.

The team policy requires that two team members complete each initial assessment. However, over the target three-month period the majority of assessments (83.3%) were carried out by a single team member. This is partly explained by a substantial proportion of assessments being carried out by the consultant psychiatrist (47.2%), who was not required to complete joint assessments.

The team uses standardised referral forms which request information about; reason for referral, any health issues, medication, and current living situation. It also requires referrers to state the reason they feel the person being referred has a learning disability. This may have partly accounted for the high percentage of appropriate referrals being made to the team (i.e., 91.1%).

The view that people with learning disabilities have a complex mixture of needs appears to be illustrated by this study. 45.1% of referrers highlighted more than one
difficulty being experienced; in addition, more than one service was requested for 19.6% of referrals. The assessment profiles suggest that a very high proportion of people assessed showed multiple problems. 80.2% were assessed as having more than one difficulty, with more than 40% having three or more problems.

There appeared to be an under representation of some ethnic groups than would be predicted from the population figures. Black Caribbean, Black African, and Indians appeared to be under represented in the referrals made to the team. Interestingly, there was also a slight under representation of white clients, 45.1% referred, compared to 58% of the local population. However, only tentative extrapolations can be made form these data for two reasons. First, information about ethnicity was not recorded for approximately 25% of referrals. Second, it cannot be assumed that the incidence of learning disabilities in different ethnic groups would perfectly mirror figures for the proportion of minority groups in the general or local population.

It is vital for health and community services to be accessible to minority ethnic groups who are a part of the community they serve. Recommendations for this service would be to make the collection of ethnicity data a priority. Increased availability and use of interpreters might also improve understanding and access for ethnic minority groups.

As predicted a high proportion (25.5%) of individuals referred to the team were experiencing difficulties expressing their sexuality. However, sexuality/sexual difficulties were highlighted in only 13.7% of referrals while the remaining 11.8% were identified at assessment. Of this 25.5%, 19.6% were experiencing difficulties
with sexually inappropriate behaviour. These individuals are at risk of being socially isolated because carers and staff members find these behaviours difficult to deal with, and may tend to keep individuals away from social situations (Burns 1993).

It is possible that there were a higher percentage of individuals experiencing sexual problems on the caseloads of team members than were reflected at referral and assessment. This is because this is a difficult and sensitive area; referrers, carers and clients may have difficulty revealing these problems until the intervention is underway. Therefore to facilitate the identification of these problems, it might be helpful for questions regarding this type of difficulty to be incorporated into the referral and/or assessment process. It is recognised that this is a very sensitive area, however given the possibility of these difficulties, it is important that they are recognised and addressed.

The large number of individuals presenting to the team with sexuality/sexual difficulties indicates that the team would benefit from having someone on the team who has specialist knowledge of, and expertise in working with this type of problem. It is anticipated that this report will be useful in supporting any future bid for finance to create a post for a specialist worker in the area of sexuality/sexual difficulties by the MDCHT for people with learning disabilities studied.
REFERENCES


