Major Research Project

Stress, Coping and Adjustment in Parental Primary Carers of Adults with Challenging Behaviour

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Small-Scale Service-Related Research Study

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Four Case Reports

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Abstract

A multivariate cross-sectional design was used to investigate the psychological impact of challenging behaviour on parental primary carers of adults with learning disabilities and challenging behaviour. The sample consisted of 54 parental primary caregivers in families containing an adult with a learning disability and exhibiting challenging behaviour, identified and recruited from 15 local learning disability services in and around the boroughs of London. Parental primary caregivers, mainly mothers, were requested to complete a booklet of self-report questionnaires, which included questions about their health, satisfaction with life, personal attitudes and traits, family and social relationships, coping styles and the nature of the challenging behaviour and learning disability in their sons/daughters. A taped interview, using a semi-structured interview schedule, was also conducted with caregivers' in their homes to explore their personal views, perceptions, needs and experiences relating to professional contact and services.

The relationships between potential stressors, coping resources, coping strategies and psychosocial adaptation were investigated using multiple regression analyses. Significant associations were found between the outcome variables of psychosomatic health and perceived satisfaction with life and the predictor variables of challenging behaviour, marital satisfaction, neuroticism and coping strategies. Taped interviews were transcribed and coded to examine any patterns in service use and professional contact, levels of satisfaction, the nature of caregivers' needs in relation to caring for their sons/ daughters and their observance of any gaps and limitations in service delivery and organisation. The implications of the study's results and findings for service organisation and delivery, clinicians and practitioners in clinical practice and also research practice are discussed.

CHAPTER ONE

Introduction

1.1 Brief Background to the Present Study

Over the last few decades, researchers and clinicians have shown considerable interest in how families are affected by the presence of a member with learning disabilities, and how such families may best be supported and helped (Byrne & Cunningham, 1985; Carr, 1985). Carr (1990) remarks that it is self-evident that the family's needs would be viewed as more urgent if the disabled member also had behavioural or psychiatric difficulties, yet there is clearly a stark absence of research literature focusing on the impact of challenging or problematic behaviour in people with disabilities on informal caregivers.

A limited number of research studies have investigated the effects of challenging behaviour on parental primary caregivers and their families, but they have been largely restricted to carers and families of children and adolescents (Quine & Pahl, 1985; Byrne, Cunningham & Sloper, 1988; Donovan, 1988). A number of researchers (Tausig, 1985; Carr, 1990) have suggested that fewer people with serious behaviour difficulties may still be at home as adults, but where such people are still at home they can present major challenges to their families (Hogg, 1987; Holmes, 1988). Professional learning disability services are more likely to see such families, particularly the main caregiver, as a high priority in relation to advice, support and help on management (Hogg, 1987).

Despite these observations, clinicians and researchers have given sparse time and attention to the needs and experiences of parental primary carers and their families in caring for their sons and daughters who exhibit challenging behaviour. It is evident that there still remains an enormous gap in the research literature on this subject area that urgently needs to be addressed. The present study is intended to add to the scanty literature in the area by focusing upon the psycho-social-cognitive impact of challenging behaviour on the parental primary caregivers of those adults with learning disabilities who also have challenging behaviour and are still living at home with their families.

1.2 Conceptualising Challenging Behaviour

Challenging behaviour is a term that has no absolute definitions because it is a socially constructed phenomenon (Zarkowska & Clements, 1987). It is a concept that has been considerably debated amongst its different users across health, education and social settings. Given that different people, or groups of people, have different ideas about what is meant by "challenging" (Qureshi, 1994), the identification of challenging behaviour tends to depend upon the standards, interpretations and values of an individual, group and/or organisation as well as resources, expertise and tolerance levels.

Research studies examining various aspects of challenging behaviour within day, community and residential settings for adults with learning disabilities have primarily focused on and restricted their coverage to behaviours which can be characterised as being socially intrusive or disruptive (eg. Harris, 1993; Murphy, Oliver, Corbett, Crayton, Hales, Head & Hall, 1993; Kiernan & Alborz, 1995; Kiernan & Qureshi, 1993). These typically incorporated aggressive, destructive and self-injurious behaviours and other socially intrusive behaviours such as persistent screaming, inappropriate sexual behaviours and wandering, all behaviours reflected in Qureshi's (1994) definition of challenging behaviour for the large-scale epidemiological study undertaken by Kiernan, Qureshi & Alborz (1989). However, studies based on parental carers and families, most typically studies of child and adolescent populations, have included an expansive range of behaviours, commonly characterised as "problem behaviour" (Carr, 1988; Sloper & Turner, 1993; Quine, 1986; 1993; Quine & Pahl, 1985). Such studies, in addition to the range of 'challenging' behaviours, incorporate behaviours such as disorders in sleeping-waking and incontinence, which increase the need for continuous parental supervision and/or their work load (Kiernan & Alborz, 1996).

The wide variation in the use of the terms "challenging" and "problem" behaviours found in the literature further reflects the ambiguity encountered in conceptualising the notion of challenging behaviour. Challenging behaviour has been defined by Emerson, Cummings, Barrett, Hughes, McCool, & Toogood (1988) as "behaviour of such an intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities" (p. 16). This definition encapsulates the pivotal point contained in the term itself, primarily that of a shift in perspective among service providers away from seeing problems as inherent qualities of people and towards focusing on how services can best respond to behaviour which poses a challenge to the achievement of an ordinary life for people with learning disabilities (Blunden & Allen, 1987). It is further intended to be applied only to a narrow range and level of problems, and, thus, target a small 'core' group of people with learning disabilities (Qureshi, 1994).

Kiernan *et al* (1989) undertook a large-scale epidemiological study of challenging behaviour. In their study, people were defined as showing challenging behaviour if they "had **at some time** caused more than minor injuries to themselves or others, or destroyed their immediate living or working environment *OR* showed behaviour **at least weekly** which required intervention by more than one member of staff for control, or placed them in physical danger, or caused damage which could not be rectified by immediate care staff, or caused at least an hour's disruption *OR* caused more than a few minutes disruption **at least daily**" (Qureshi, 1994, p. 28).

Emerson, Felce, McGill & Mansell (1994) state that "seriously challenging behaviour can blight the lives of service users and those caring for them in a number of ways" (p.7). Behaviours identified as "challenging" may have adverse effects upon the individual's and/or upon others' physical well-being, lifestyle or quality of life, psychological well-being and personal development (Zarkowska & Clements, 1987; Emerson, Felce, McGill & Mansell, 1994). Evidently, people identified as showing challenging behaviour often present services and their carers with multiple challenges. These challenges are likely to further multiply if the person also has poorer skills and abilities in the domains of mobility, self-help skills and language, which Kiernan & Alborz (1996) have found to be associated with higher levels and persistence of challenging behaviours.

1.3 The Prevalence of Challenging Behaviour

In a large-scale study (Kiernan, Qureshi & Alborz, 1989) of children, young adults, and adults known to or within services for people with learning disability in the North Western Regional Health Authority, Kiernan & Qureshi (1993) found 734 (16.7%)

people with learning disabilities had been identified by day and residential services as having challenging behaviour. These individuals formed 30% of the long-stay hospital and 13% of the community population. However, Qureshi (1994) found, using her criteria of identifying people with challenging behaviour, 291 (42%) of the 734 identified people **actually showed** challenging behaviour, of whom 241 were adults. Qureshi (1994) shows that they form a higher proportion of the hospital than the community populations, with 14% of people living in hospital showing challenging behaviour compared with 5% in the community. About 52% (124) of all adults with challenging behaviour were living in hospital, 27% (66) in the community and 21% (51) in their family home. The ratio of adults in hospital settings rose steadily with age and men were more likely to be placed than women (Qureshi, 1994). These figures clearly illustrate that there are approximately 51 families resident in a typical health district area who care for an adult member with a learning disability and challenging behaviour (Qureshi, 1994).

Kiernan *et al* (1989) reported that different rates of seriously challenging behaviour are found in adult mobile and non-mobile people. They found, in mobile people, physical attacks (23.3%) and non-compliance (21.3%) were the most frequent, with destructiveness (17.2%) and self-injury (14.9%) taking the lowest rankings. In non-mobile adults, self-injury (40.5%) was strikingly the most serious problem, but physical attacks (21.4%) were also common among this group. More than one type of challenging behaviour was found in the majority of adults: amongst seriously challenging behaviours, 26.3% of people showing destructive behaviour were also identified as making physical attacks and 25.4% engaged in self-injury (Kiernan, *et al*, 1989).

Using data from their longitudinal study, Kiernan & Alborz (1996) illustrate the nature and persistence of challenging and problem behaviour, based on parent reports in 1988 and 1993, in a group of 34 young adults with learning disabilities living in their parental home. In 1988, 24 (71%) parents reported physical injury, 17 (50%) destructive behaviour, 20 (59%) self-injurious behaviour, 15 (44%) problems with supervision and 26 (76%) night disturbance. In 1993, 21 (62%) parents reported physical injury, 16 (47%) destructive behaviour, 15 (44%) self-injurious behaviour, 13 (38%) problems with supervision and 28 (82%) night disturbance. Kiernan & Alborz's (1996) found physical injury, destructive behaviour and self-injurious behaviour was reported by over 50% of parents in 1988, but in 1993 fewer parents reported the occurrence of these particular behaviours. Parents reported fewer problems with supervision and more with night disturbance in 1993 compared to 1988. Kiernan & Alborz' (1996) study has illustrated the persistence and change in the occurrence of challenging and problem behaviour over time, which have also been shown by previous researchers (Emerson, Robertson, Letchford, Fowler & Jones, 1996; Murphy *et al*, 1993; Leudar, Fraser & Jeeves, 1984).

In summary, the figures, patterns and trends reported in this section clearly emphasise the extent to which challenging behaviours in adults with learning disabilities can pervade and impact upon learning disability services in hospital and community settings and also in families. Further, given that the total number of adults with learning disabilities and challenging behaviour living at home with their families is gradually increasing due to the rapidly growing philosophy and implementation of care in the community, the resultant impact on parental primary caregivers and their families needs to be better understood.

1.4 The Philosophy of Care in the Community

Since the 1970s, there has generally been a shift in direction in services for people with learning disabilities towards the closure of institutions and the development of care in the community (eg. Department of Health, 1989; HMSO, 1971, 1990). The parallel growth of a veritable catalogue of criticisms of institutional forms of care for people with learning disabilities has also been observed (Emerson, Felce, McGill & Mansell, 1994). The segregation of their residents from the outside world, the separation of residents from their family and friends and from the general life of the community are only some of the criticisms directed against institutions. Long-stay institutional environments are clearly no longer looked upon as desirable, resourceful or adequate by policy makers and service providers in responding to the needs of people with learning disabilities or their families.

The wide range of criticisms directed against institutional settings essentially paved the way for the emergence of community-based services for people with learning disabilities. Traditionally, people with learning disabilities were seen as disabled first whose needs could only be met in long-stay hospital-like settings. They are now seen as people first, with "the right to lead a valued ordinary life, based on the belief in their equality as human beings" (Ramon, 1991), and who should be cared for in and by the community. Services and policy makers stressed the necessity of innovative models of service delivery that would ensure provision is made on an identified needs-led basis as well as adhere to the principle of normalisation (Wolfensberger, 1980; 1983) and the right to an "ordinary life" (King's Fund, 1980) for people with learning disabilities. Inherent within this conceptual framework was the recognition that "people with mental handicap have a right to enjoy normal patterns of life within the community and people with mental handicap have the right to be treated as individuals with dignity and respect" (King's Fund, 1980, p.6).

Alongside these considerations of policy and models of service delivery, Wolfensberger's (1980, 1983) principles of normalisation and social role valorisation permeated services during the 1980s. The "Ordinary Life" project paper (Kings Fund, 1980) had a huge impact on services and the movement towards community care. In many services, O'Brien's (1987) "five accomplishments" relating to community presence, relationships, choice, competence and respect, also became important aims in relation to community living and the development of community support services.

The widespread adoption of these doctrines in community-based services stresses the serious attempt being made by policy makers to enable people with learning disabilities to experience the patterns of living, learning, working and enjoying their leisure time typical for people of their age in the wider community (Emerson, Felce, McGill & Mansell, 1994). It reflects a willingness, on the part of policy makers, to ensure that people with learning disabilities and their families receive cost effective, high quality care, whether that be provided by the health service, social services, or the local voluntary and private service.

Most people with learning disabilities are now part of local communities as opposed to being segregated in hospitals or institutional settings. The move away from institutional settings and towards care in the community for people with learning disabilities is obviously a reflection of the changes in attitude in mainstream sectors, policy makers and services. Unfortunately, however, the situation is notably different for people with learning disabilities and challenging behaviour, despite the fact that they represent around one in six of the population covered by learning disability services (Qureshi & Alborz, 1992). The philosophy of care in the community and the rights to an “ordinary life” were not extended to people showing challenging behaviour. Indeed, in the 1971 White Paper (HMSO, 1971) people with challenging behaviour were seen as remaining in institutional care, even forming the basis of support for long-stay hospital environments. This was apparently due to the difficulties envisaged by policy makers in developing services in the community for these individuals and it was only during the 1980s that their entitlement to remain in the community and an “ordinary life” was reluctantly but gradually recognised (Emerson, Barrett, Bell, Cummings, McCool, Toogood & Mansell, 1987).

The gradual recognition and acceptance of the entitlement of people with challenging behaviour to be cared for by and in the community was particularly instigated by the work of Blunden & Allen (1987). They rooted their approach in the “Ordinary Life” philosophy (King’s Fund, 1980) by recapitulating that people with challenging behaviour had the same human value as anyone else, have a right and a need to live like others in the community and require services which recognise their individuality. Blunden & Allen (1987) also considered the implications of these values for service objectives in terms of O’Brien’s (1987) five accomplishments. They vividly remind us of the fact that these are aspects of life relating to community presence, relationships, choice, competence and respect, which services should help people with challenging behaviour to achieve. Yet, as will be seen in the following sections, the reality has still fallen far short of such aims for the vast majority of people with challenging behaviour, carrying clear implications for both parental caregivers and their families as well as current service policy and practice.

1.5 Policy and Service Delivery

The practice of community care, as demonstrated and critiqued in the previous section, has clearly been hindered or delayed in terms of both policy and service delivery for people with challenging behaviour in learning disability services. As deinstitutionalisation and the growth of service provision based in the community has accelerated, often due to financial factors (Department of Health, 1989), people with less severe learning disabilities and without behavioural difficulties have tended to lead the move from institutional to community settings (Emerson, Felce, McGill & Mansell, 1994). This means that the ratio of people with severe learning disabilities and behavioural difficulties in institutional populations has risen in disproportionate terms and continues to do so.

Yet, in addition to the resistance shown in government policy towards the resettlement of people with severe learning disabilities and challenging behaviour, there has been an apparent reluctance of local services to learn or gain experience in serving those with individuals with more serious disabilities and challenging behaviour. In fact, their very resistance and reluctance has actually been used to support arguments for the continuing need to provide institutional services for people with serious disabilities. The difficulties in conceptualising, defining and understanding the causes of challenging behaviour (Baumeister, 1989) have also contributed to the prejudice and exclusion of these sectors of the learning disabilities population from community services. It was generally accepted that the community itself as well as local services were 'not ready' to support people who challenge services (Emerson, Felce, McGill &

Mansell, 1994) and would essentially be better placed in long-stay hospital or institutional environments.

In spite of the existing difficulties in community attitudes and service delivery for people with challenging behaviours, the need for different and better services is obviously apparent as the option of long-stay hospitals is generally no longer available. Members of this client group can currently still be found in traditional service provision, such as special hospitals, private hospitals, locked wards, or equivalent institutional environments. Nevertheless, as the replacement of long-stay hospital or institutional settings continues, more people with seriously challenging behaviour are returning to their home communities. Consequently, local services are increasingly needing to become 'self-sufficient' and provide their services to all people with learning disabilities including those with seriously challenging behaviour (Emerson, Felce, McGill & Mansell, 1994).

Thus, as the government's commitment to community care for people with learning disabilities continues (DHSS, 1985), the problem of providing a service for those who exhibit challenging behaviour is one with which many health authorities are still faced. It has been seen that many advances have been made in terms of policy development and service delivery in relation to care in the community, but it is apparent that people exhibiting challenging behaviour have become victims in the process of this very progress, and their rights and needs have been slow to receive recognition, acceptance and resolution at the level of service policy and delivery.

Parental caregivers and their families will clearly bear the brunt of the responsibility in providing “care in the community” for these individuals as they are being excluded from community services because of inability to manage the behaviours and institutional settings because of their continued closure programmes. Since the late 1980s with re-settlement and the development of community services, a look at epidemiological research outcomes provides sufficient evidence that a substantial and increasing proportion of adults with challenging behaviour are inevitably finding themselves moving back into their parental homes (Qureshi, 1994; Kiernan & Qureshi, 1993). Yet scarcely any attention has been given to the roles and needs of informal caregivers (Kiernan & Alborz, 1995), despite the clear impression that the goals of current service policy and delivery for adults with challenging behaviour are having a significant impact on parental carers and families.

1.6 The Impact of Care in the Community on Informal Caregivers

Since 1971 the role of parents and the family has been increasingly seen as a central element in the development of care in and by the community for people with learning disabilities. The White Paper “Better Services for the Mentally Handicapped” asserted that “each handicapped person should live with his own family as long as this does not impose an undue burden on them or him and he and his family should receive advice and support” (HMSO, 1971, para 40). This position has since been elaborated to include care by all the informal social support networks surrounding the family, but there is some evidence suggesting that the size and nature of the social support network available to the family are likely to change as their children enter adulthood.

For example, MacLachlan, Dennis, Lang, Charnock & Osman (1987), five mothers of adults with disabilities stated that “whilst their children were young, they were accepted more easily by other families with 'normal' children ... they did not feel as isolated and embarrassed then as they do now they are adults ... the medical profession does not understand the impact on a family of having a child who is learning disabled, and the needs of that child and the family within which it lives ... while the child is young, there is fairly good paediatric care in all fields, but once adult the support ceases" (p.5). This clearly reflects that the sources of support from professional and informal networks do alter considerably when children enter adulthood and, if the person also shows challenging behaviour, it is perhaps obvious that the acute and chronic nature of such stressors make the parents and families of adults with challenging behaviour more vulnerable to distress and ill-health.

The Griffiths' report on community care emphasised that "the first task of publicly provided services is to support and where possible strengthen these networks of carers" (Griffiths, 1988, p5) and the White Paper "Caring for People" saw helping carers to maintain care as both a "right and a sound investment" (HMSO, 1989, para 2.3). Yet the reality of service provision seems to fall far short of this. For instance, Qureshi (1990), in her analysis of services provided to young adults with challenging behaviour living with their parents, concluded that:

> "perceived service deficiencies include: day services which may be unsuitable, are not flexibly structured and may even exclude the person entirely; a widespread shortage of short-term and long-term residential facilities in the community; an incapacity to cope with behaviour problems in many existing facilities; a failure to give parents useful advice on handling behaviour problems at home; insufficient help from social workers and community nurses" (p.1).

The 1990 NHS and Care in the Community Act (HMSO, 1990) also gave the right to carers to be involved in the process of planning care. The Act suggested that the needs and views of carers should be given consideration in planning services for people with disabilities and that they should be helped by being given advice and practical help. However, there is little research evidence to suggest that the role of carers is clearly conceptualised, that their views are given prominence in service planning, or that their needs are adequately recognised (eg. McGrath & Grant, 1992; Twigg & Atkin, 1991, 1994). Studies of a range of carers providing informal care for adults have demonstrated that the overwhelming burden of care falls on the family, and especially on women within the family, rather than on broader informal networks. MacLachlan and her peers felt, as mothers, "it was their task to keep the family together and make sure that their presence did not influence the normal life of the family" (1987, p.5). In the case of adults with learning disability and challenging behaviours living at home, this means that the mothers usually shoulder the responsibility of care (eg. Glendinning, 1983; Parker, 1990; Qureshi, 1993) yet their roles and needs have received relatively little attention from researchers.

Over recent years, there have been many examples of innovative developments in community-based services for people who are learning disabled and exhibiting challenging behaviour (Ward, 1982). Services for people with challenging behaviour have engaged policy makers and researchers in substantial efforts during the last decade (eg. Department of Health, 1993; Emerson, McGill & Mansell, 1994; Jones & Eayres, 1993; Kiernan, 1993). This work, however, focused mainly on the philosophy, design and evaluation of community based residential services. Relatively little attention has been devoted to the role and needs of informal carers, even though a substantial proportion of people with learning disability and challenging behaviour are living in their family homes. For example, Kiernan *et al* (1989) found that of 520 adults with learning disabilities and challenging behaviour, 138 (26%) were living in their family homes. These numbers are further increasing in parallel with the number of people moving away from institutions and those remaining in their parental home upon leaving school. Thus, there still remain many gaps in knowledge as to whether the services being provided are what carers and families actually want or need. It is important to judge the impact and success of a new service on informal carers by directly asking the parental carers and their families, who are at the receiving end of community-based services, about their practical needs and views (Humphreys, Lowe & Blunden, 1985).

Although the role of the main carer and family in the determination of the quality and quantity of learning disability services is central in the issue of learning disability service provision, there is still some way to go before informal caregivers are afforded regular opportunities to make their needs known, rather than accepting the more traditional and passive role of recipients of services (Humphreys *et al*, 1985). This latter is likely to be particularly detrimental when professional and service assumptions about the needs of individuals and their carers and families are being imposed in the absence of a sound knowledge base acquired from research findings, which seems to be a true picture in relation to people with challenging behaviour living in the community in their parental homes. The advice and support that has been imposed on informal carers is based on very little research evidence as to what families actually want or need (Conroy,1985). This is even more apparently striking in the areas of challenging behaviour, where the needs of individuals or their carers are clearly being overlooked by services.

The absence of appropriate and necessary support can set off a number of chain reactions in which, ultimately, "the needs of the service user remain unmet and carers remain faced with a distressing, stressful and (at times) dangerous situation" (Emerson, Felce, McGill & Mansell, 1994, p.7) and the consequent pressure to contain the behaviour by increasingly restrictive means obviously becomes more urgent. Challenging behaviour is a major cause of stress experienced by carers (Quine & Pahl, 1985) and one of the main predictors of whether parents will seek a residential placement for their son or daughter (Tausig, 1985). Services provided to young adults with challenging behaviour living at home with their parents are often insufficient, especially in the area of providing advice or assistance within the parental home to effectively manage episodes of challenging behaviour (Qureshi, 1990).

People with challenging behaviour are at significantly increased risk of institutionalisation and exclusion from community-based services (Lakin, Hill, Hauber, Buininks & Heal, 1983; Schalock, Harper & Genung, 1981). Once admitted to institutional care they are likely to spend the bulk of their time in materially deprived surroundings, disengaged from their world and avoided by staff (Emerson, Beasely, Offord & Mansell, 1992; Felce, Thomas, de Kock, Saxby & Repp, 1985). This is obviously a serious shortcoming as it severely opposes the existing philosophy of community care, the principle of normalisation and the right to an "ordinary life", but are the likely end consequences of informal care if parental carers and their families are not properly supported by services. It is crucial to provide comprehensive, high quality services to parental primary caregivers and their families that enable them to feel supported by the system and, in turn, provide support to their sons/daughters.

Qureshi (1990) states that local services are already struggling to provide for the many people with challenging behaviour who continue to live with their families. Given this struggle to provide an appropriate service to this population group, it becomes a crucial issue when community services are unable to contain or cater for the needs of people with challenging behaviour or their carers and families. Parental caregivers have to shoulder the extra burden of caring for their sons/daughters during the day, for those who have been excluded from services, in addition to the usual times. Yet, their needs are not adequately questioned or addressed because service providers are themselves struggling to provide an appropriate service and rely upon parents to drawn upon their informal support networks. Parents are then likely to have nowhere else to turn to, given that their informal sources of support tend to diminish during their son/daughter's adulthood.

Furthermore, as Turnbull, Brotherson & Summers (1985) state, "handicapped individuals are entitled to normalisation, so, too, are their families" (p.138). This right should extend, in practice, to people who exhibit challenging behaviour and to their parental carers and families. Parental carers and families of people also have the right to an "ordinary" life rooted within the community without feeling victimised and marginalised. In considering the impact and implications of deinstitutionalisation, clinicians and researchers and decision makers must address the needs, feelings and reactions of carers and families (Conroy, 1985). In his consideration of family attitudes and reactions to deinstitutionalisation, he shows that "families of handicapped persons have received woefully little attention from the research community (p.149). He concludes "we professionals have heeded little the concerns of parents in our rush to deinstitutionalise and normalise living and learning environments for handicapped citizens" (p.151) and that it is "now time to listen carefully to the needs and feelings of families (p.151).

1.7 Understanding the Psychological Impact of Challenging Behaviour on Caregivers

The field of learning disability has witnessed a radical shift in paradigm in relation to its history and philosophy of care. Services for people with learning disabilities have moved their focus away from providing care in long-stay institutional settings towards community based practice. In parallel to this, theoretical focuses of stress and family functioning have also seen a remarkable change in emphasis in the area of family studies of people with learning disabilities. This change in direction can be observed in the research studies that have undertaken an investigation of the impact of learning disabilities on the physical and mental health and well-being in families containing a member with learning disabilities.

Traditionally, research studies on family stress and functioning have generally reflected the homogenous assumptions that researchers and practitioners have made about the impact of learning disabilities including problem and challenging behaviours on informal caregivers. More recently, however, the recognition on the part of researchers and practitioners of there being wide variations in stress and familial functioning in caregivers and families has been discerned in the research literature. This has subsequently affected significant changes in focus and emphasis, theoretically and empirically, in researchers investigating the impact of learning disabilities on informal carers and their families.

In this section, I will draw upon the available literature on stress and psychological functioning in families of people with learning disabilities including problem and challenging behaviour. The aim of this section is to review the relevant literature on the impact of problem and challenging behaviour in adults with learning disabilities on the psychological health and well-being of parental caregivers and their families.

There is a stark absence of existing research literature examining the impact of challenging behaviour in adults with learning disabilities on parental caregivers and their families (eg. Kiernan & Alborz, 1995; Hubert, 1991). Given the dearth of research studies in this particular population and age group, this review of the existing literature will draw upon the findings of research studies that have examined the impact on parental primary caregivers and their families of different aspects of learning disabilities, including single diagnostic categories such as Down's syndrome, in children, adolescents and adults.

A considerable body of literature has emerged in recent years on factors related to stress and family functioning in families of children and adolescents with disabilities including behaviour problems (Quine & Pahl, 1991; Sloper & Turner, 1993). Early research studies tended to adopt a 'pathological approach' in examining the effects of children with disabilities on families and, by viewing families as a homogenous group, assumed such families are subject to high levels of stress which cause impairment among family members (Mash, 1984; Turnbull, Brotherson & Summers, 1985). So their focus subsequently had often been on variables related to poor outcome for families, rather than identifying factors related to successful adaptation (Byrne, Cunningham & Sloper, 1988).

Carr's (1990) review of the literature examining the effects on the family of a person with learning disabilities and behaviour problems reflects many of these traditional and still existing assumptions relating to families containing members with disabilities. Although such studies are extremely limited in number as very little attention has been paid to the particular question of the impact of behaviour problems, they show that behaviour problems affect family functioning and family stress, particularly illustrated in families of children rather than of adults (eg. Margarit, Shulman & Stuchiner, 1989; Quine, 1986; Quine & Pahl, 1985; Saxby & Morgan, 1993), clearly reflecting the dearth of similar studies of families of adults with challenging behaviour. Carr (1990) emphasises that parents of children with behaviour problems seek out-of-home placements more often than parents of children with learning disabilities without behavioural or psychiatric difficulties. Byrne *et al* (1988) described children with severe behaviour problems as having pervasive and lasting effects on their parental caregivers and families, and restrict social activities, leading to poor relationships with friends or family, and are associated with maternal distress and depression.

In a study of 200 families with severely learning disabled children living in two health districts in South East England, Quine & Pahl (1985) investigated the effects of behaviour problems in children on their mothers, using the Malaise Inventory (Rutter, Tizard & Whitmore, 1970). They found that behaviour problems to be very significantly associated with mother's stress scores: mothers of children with severe behaviour problems had a mean Malaise score of 7.03, those of mildly behaviourally disordered children a mean score of 5.62 and those of children with no behaviour problems a mean score of 4.66. Using stepwise regression analysis, behaviour problems emerged as the most important stress inducing factor, followed by night time disturbance, social isolation, adversity in the family, multiplicity of impairments, difficulty in settling the child at night, problems with the child's health, problems with the child's appearance, and money worries. In this study, behaviour problems in the children were the major contributors of stress in the mothers.

Saxby & Morgan (1993) interviewed the parents of 68 young children with learning disabilities to assess the number and type of behaviour problems that their child exhibited as well as the parents' perceptions of their ability to cope with the behaviours. The authors found that scores of parents' perceived coping skills and malaise were associated with the number and types of behaviour problems. Parents who reported their child hurt themselves, hurt others or had a sleep problem were likely to have a higher malaise score.

Using a sample of 39 families of children with moderate learning disabilities, Margarit *et al* (1989) investigated the impact of learning disabilities and behaviour problems on family climate and feelings of stress among parents of children with learning disabilities who also exhibit behaviour problems. They divided their sample into two groups: children showing disruptive behaviour (n=17), to the extent that they were admitted to a specialised educational system, and children without such behavioural difficulties (n=22). Margarit *et al* (1989) examined the interrelations of the children's pathology and family climate variables with the levels of parental stress. Although the children with disruptive behaviour were described by their parents as more hyperactive and aggressive, and by their teachers as more distractible and dependent on adults, they found no significant differences between the two groups of parents in measures of stress, but the level of pathology in children and aspects of family climate predicted levels of stress in parents.

The authors suggest that the special school attended by the children with behaviour problems may have acted as a buffer for the parents, relieving them of the stress that the children imposed. Clearly, however, further research needs to address the interrelations between children's pathology, family climate, and parental feelings of stress. Margarit *et al*'s findings suggest that problem behaviours do not inevitably lead to stress and ill-health in parental caregivers and their families, but potential factors that may buffer or mediate the effects of stress need to be identified and investigated.

Recently, discarding assumptions about homogenous families and pathological responses to stressors, investigators have sought to discover which families and family members are most vulnerable to stress and which characteristics of families are related to variations in the amount of stress reported (Sloper, Knussen, Turner & Cunningham, 1991; Sloper & Turner, 1994; Snowdon, Cameron & Dunham, 1994). Such researchers conclude that stress is not an inevitable consequence for families with children with disabilities, but can be predicted through factors such as the presence of multiple stresses, life-cycle stages, family's interpretation of the situation and the integration of the family prior to the birth of the disabled child (Turnbull, Brotherson & Summers, 1985). They emphasise the importance of resources and coping factors which may moderate or mediate the effects of stress (eg. Donovan, 1988; Dyson, 1993; Friedrich, Wilturner & Cohen, 1985).

Friedrich, Wilturner & Cohen (1985), in their study looking at four dimensions of coping resources (utilitarian resources, energy/morale, general and specific beliefs and social support) in a sample of 140 mothers of children with learning disabilities, measured a variety of child factors including medical factors such as severity of handicap and hospitalisation, behaviour problems, and family coping resources such as level of parental education and income, health, social support and general and religious beliefs, and the effect of these on parental functioning. In a multiple regression analysis, the authors found medical involvement of the children had a significant overall effect on parental functioning, accounting for 17% of the variance, but behaviour problems added a separate contribution of an additional 10%. Nonetheless, Friedrich *et al* (1985) found the coping resources available to the family were as good a predictor of parental functioning as were child variables, with three out of the four categories of coping resources proving to be significant contributors in a regression analysis and contributed additional variance beyond that of behavioural and physical problems of the child with the learning disability.

The recognition that a negative outcome is not inevitable in families of children with disabilities, and that outcomes range from successful adaptation to maladaptation, has led to a focus on models of stress which can explain this variation in response (eg. Lazarus & Folkman, 1984; McCubbin & Patterson, 1983a). Additionally, recent work has emphasised the importance of viewing the family as a dynamic transactional system, in which all elements of the system are assumed to interact with and influence all other elements, as the most fruitful approach to understanding the complexity of human behaviour (eg. Sameroff, Seifer & Zax, 1982). The adoption of such a complex, multivariate standpoint which emphasises the differences as well as similarities between carers and families of people with learning disabilities has clearly been an important one.

Using a sample of 50 families who utilised the services of a respite care programme, Snowdon, Cameron & Dunham (1994) conducted a descriptive correlational study in order to examine relations between stressors (child disability-related conditions and behaviour problems), internal (hardiness, mastery/health, esteem/communication) and external (social support) coping resources, and the outcome variable of satisfaction with family functioning of families caring for children with learning disabilities. In a hierarchical multiple regression analysis, the authors found that the child's conditions and behaviours were not significantly related to satisfaction with family functioning. Despite facing the challenges of stressors arising from the experience of caring for children with varied handicapping conditions including behaviour problems, these families reported satisfactory internal coping resources such as hardiness, mastery and health, esteem and communication, and satisfaction with family functioning. Their study clearly illustrates the importance of internal and external coping resources in mediating the effects of exposure to stress in families caring for children with learning disabilities including behaviour problems.

Sloper *et al* (1991), in a study of families of children with Down's syndrome, used a cross-sectional multivariate design to investigate the relationships of parent, family and child characteristics to outcome measures of psychosomatic symptoms of stress and perceived satisfaction with life in both mothers and fathers. They found, for mothers, after neuroticism, the children's level of behaviour problems, excitability and self-sufficiency were strongly related to outcome, but coping strategies, family relationships and socio-economic factors also showed significant effects. The authors found, for fathers, the marital relationship was most strongly associated with satisfaction with life, as well as high perceived strain from life events, financial problems, high use of passive acceptance in coping with child-related problems and high neuroticism scores were associated with lower satisfaction with life.

Sloper *et al* (1991) further again found that the most important predictor of stress for mothers was neuroticism, as well as behaviour problems, lack of a car and greater use of wishful thinking as a coping strategy. The authors suggest that the inclusion of behaviour problems in the regression equation suggests that these could be a major source of stress for mothers. For fathers, the variables most strongly associated with stress were neuroticism and the marital relationship. The findings of these authors clearly show the importance of adopting a multivariate approach to the study of stress in families containing members with learning disabilities, including problem behaviours, in assessing the interrelationships between stressors, coping resources and outcome measures of stress and satisfaction with life.

Using the same sample, as described above, Quine & Pahl (1991) investigated variables associated with maternal stress and those that might buffer the effects of stress among 166 mothers caring for a child with severe learning difficulties. The following five categories of coping resources, as identified by Lazarus' (1966; see also Folkman *et al*, 1979) transactional model of stress, were included in the study: (1) the mother's social class and appraisal of financial worries, (2) physical health, (3) social support, (4) acceptance of and adjustment to the child, and (5) assessment of coping skills. Four of the 5 coping resources proved to be significant contributors in a hierarchical regression analysis of stress scores, contributing additional variance beyond that of behavioural and other child characteristics, and explained 55% of the variance in the stress scores. Quine & Pahl's findings support Lazarus' (1966) model of stress and coping, and their choice in relation to the methodological and theoretical framework adopted reflects the change in direction in studies on families containing members with learning disabilities (see above).

Unfortunately, however, advances have been slow, a state of affairs reflected in the population of carers and families of people with learning disabilities who also exhibit challenging behaviour. Thus, in relation to carers and families of people with learning disabilities who also exhibit challenging behaviour, considerable focus has been placed on the nature and level of problematic or challenging behaviour of the family member with the disability as being one of the major stressors related to outcome in terms of family functioning and parental health and well-being.

Recent research studies have shown that a negative outcome in response to potential stressors is not always inevitable and there are variations in the health and well-being of caregivers and their families (Sloper *et al*, 1991; Sloper & Turner, 1991; Sloper & Turner, 1994; Thompson, Gustafson, Hamlett & Spock, 1992). These research studies have made important contributions to the understanding of parental health and well-being as well as their families in relation to potential stressors by taking into account the possibility of other factors acting to moderate or mediate the effects of stress. Nevertheless, they have focused on carers and families of children and adolescents with specific disabilities (eg. physical) or diagnoses (eg. Down's syndrome) as well as general learning disabilities, as opposed to carers of adults with learning disabilities who also exhibit challenging behaviour, although clearly demonstrated to be a vital and crucial area of study for researchers, as emphasised by Kiernan & Alborz (1995) and Hubert (1991).

Hubert (1991) describes the experiences of twenty families who have, living at home, a teenager or young adult with severe learning disabilities who has been classified by the professional as "severely" or "profoundly" learning disabled, and who also has "serious behavioural problems" of some kind. Hubert states that these are unusual families because they are part of a tiny minority of parents who keep their severely mentally handicapped and very difficult children at home into adulthood. Hubert documents the lives of these families, and the major, uphill struggle they have to keep their children at home, often with little or no support from the health and social services. She states that the experiences and feelings of these particular parents can shock - "quite honestly, I'd rather give him an overdose, then see him go in there" (back cover) appears to reflect the state of desperation and helplessness that such parents and families can be submerged in.

Hubert (1991) found that mothers faced tremendous difficulties in balancing their own needs against the needs of their sons/daughters with the learning disability. In other words, mothers' needs for sleep, leisure, relaxation, time alone or with partners, family and friends directly conflicted with their sons/daughters' needs for love, comfort, attention, care and practical help. Parents further experienced trauma and distress in the process of having to rely upon professionals and services to provide the much needed respite care and support for their sons/daughters. Parents felt that it was particularly when their sons/daughters had entered their adulthood that their need for help and support was at its peak, but it was at this very stage that they found the provision of services to be the most haphazard and uncoordinated. Hubert (1991) points out the lack of co-ordination between the various services - Health, Social Services, Education and Voluntary Agencies - is clearly one of the major difficulties faced by parents and families in their struggle and efforts to obtain adequate services for their adult sons/daughters with the learning disability. She highlights the need for "key" or "link" person for such families to serve as a link to all the available services.

Hubert's (1991) study vividly and poignantly describes the psychological, social and cognitive, impact on parental caregivers and families of having an adult with severe learning disabilities and challenging behaviour. Her anthropological approach to her study provides both richness and valuable insight into this population group, although it is very difficult to generalise her findings due to the very small sample size used.

Kiernan & Alborz (1995), based upon a large-scale epidemiological investigation of challenging behaviour in people with learning disability and a follow-up of an earlier study, investigated the impact of challenging behaviour on 33 parental caregivers and their families in young adults with learning disabilities living in their parental home, by seeking parents' views on services, and their views and expectations concerning alternatives to family care for their sons and daughters (Qureshi, 1993). The authors paint a picture of the experience and lives of these families and, from this, draw out implications for services and additionally make recommendations about how the services to these families and to their sons and daughters can be improved.

In addition, Kiernan & Alborz (1995) used a range of standardised measures of parental adaptation to their sons or daughters, parental coping strategies, adaptation and family relationships. They found that mothers with higher scores for Passive Acceptance as a coping strategy to deal with the challenging behaviour exhibited by their sons and daughters tended to have higher scores on a stress measure and report a lack of energy. This association was mainly found in parents of adults who had less severe challenging behaviour, were mobile and could feed themselves independently. Those parents who favoured Practical Coping as a way of coping tended to have lower stress scores and suffer less likely from psychological distress, tending to be parents of adults who were severely disabled, having limited communication and requiring assistance with feeding. Mothers scoring high on the Stoicism coping style were more likely to feel that their general health was good, and this was more characteristic of mothers of more sons and daughters with milder learning disabilities and so required less supervision.

Kiernan & Alborz' (1995) findings have shed considerable light in relation to the impact that challenging behaviour in adults can have on the physical and psychological adaptation of parental caregivers and their families. However, as with Hubert's (1991) study, their findings cannot be generalised to the wider population of informal carers of adults with challenging behaviour of all ages. Nevertheless, they have provided an extremely important and useful starting point. Systematic and multivariate research is still clearly and urgently needed to identify the moderating and mediating factors to the potential stressor of challenging behaviour in relation to outcome in caregivers in terms of health and well-being. The precise characteristics which are most likely to put families at risk are ill-defined and the relationship between interrelated risk factors such as severity of learning disability and challenging behaviour has not been sufficiently investigated. Similarly, family characteristics, such as social class, marital status and social support, found to relate to stress, are likely to be interrelated. It follows that studies measuring a wide range of variables and employing multivariable analyses are needed to discover which of these aspects or variables are most strongly related to outcome (Sloper *et al*, 1991), yet it is also important to realise that in such approaches the distinction between predictor/independent variables and outcome/dependent variables, perhaps unavoidably, does get blurred.

1.8 A Conceptual Model for Examining the Impact of Challenging Behaviour on Caregivers

Most early research on parents caring for a person with a disability was conducted atheoretically, which made it virtually impossible to use research findings to guide policy and intervention, but relatively recent research has become theory-driven, using both models of stress and models of the family. Different theoretical models have been used in researching carers and families of people with disabilities, resulting in a number of separate bodies of literature (Beresford, 1994). Family models which have been used include family life cycle theory (eg. Turnbull, Summers & Brotherson, 1986), family systems models (eg. Olson, Sprenkle & Russell, 1979; Kazak, 1986), models of stress, coping and family ecology (Crnic, Friedrich & Greenberg, 1983) and the ABCX model of family stress and adaptation (Lavee, McCubbin & Patterson, 1985; McCubbin, 1988).

Significant insights have been gained into the dynamics of family life and the ways in which families react to stress by these models, but certain factors prohibit their use to investigate the psychological impact of potential stressors on individual coping and adaptation to health. For instance, researchers undertaking studies of families have given diminutive attention to the role of extrafamilial and intrapersonal factors in mediating the effects of stress. Further, such family approaches have been slow to encapsulate the notion of coping, partly reflecting the homogenous and pathological assumptions that researchers and practitioners traditionally made about families containing a member with a learning disability. More recently, the focus has been on family dynamics and the differential effect of family types on the experience of stress, and, if coping has been considered, it has been in terms of strategies which seek to maintain family stability rather than individual well-being. In such research, the focus has typically been on mothers and, too often, "mother" has been symbolically equated with "family" without adequate recognition of individual family members and hence of the existence of multiple realities within a given family (Turnbull, Brotherson & Summers, 1985). Family models, thus, define the outcome of coping in terms of family functioning as opposed to individual health adaptation.

Since the mid 1980s, Lazarus' (1966) process model of stress and coping, embedded in a theoretical cognitive framework, has been utilised in research into families containing members with disabilities. It is widely used and researchers have proclaimed it to be the most validated and comprehensive model of stress, coping and adjustment (Slavin, Rainer, McCreary & Gowda, 1991). Figure 1.1 is a representation of this model, taken from Beresford (1994), which has clearly established a number of advantages over the family-based models. For example, the model was originally developed and formulated within the theoretical framework of stress and coping, unlike the family-based models, where coping was inadequately "appendaged" onto its existing conceptualisation. Further, Lazarus' model is concerned with the coping strategies an individual, as opposed to the family, uses in response to stressful encounters or situations. Given that the burden of care often falls on the main caregiver, usually mothers, it is important to take an individual stance in assessing psychological adaptation and styles of coping. The model advocates the role of intra-personal and socio-ecological factors in mediating stress-adjustment relations and, additionally, conceives the individual as actively and creatively seeking to manage stress. As the model is not exclusive to families with a disabled member, researchers have been able to draw upon a rich variety of general research findings to inform their investigations. Given the apparent limitations of the family-based approaches and the advantages of the process model of stress and coping, the present study adopts the latter as a means by which research into parental primary carers and families of adult members with learning disabilities and challenging behaviour can be organised, understood and investigated.

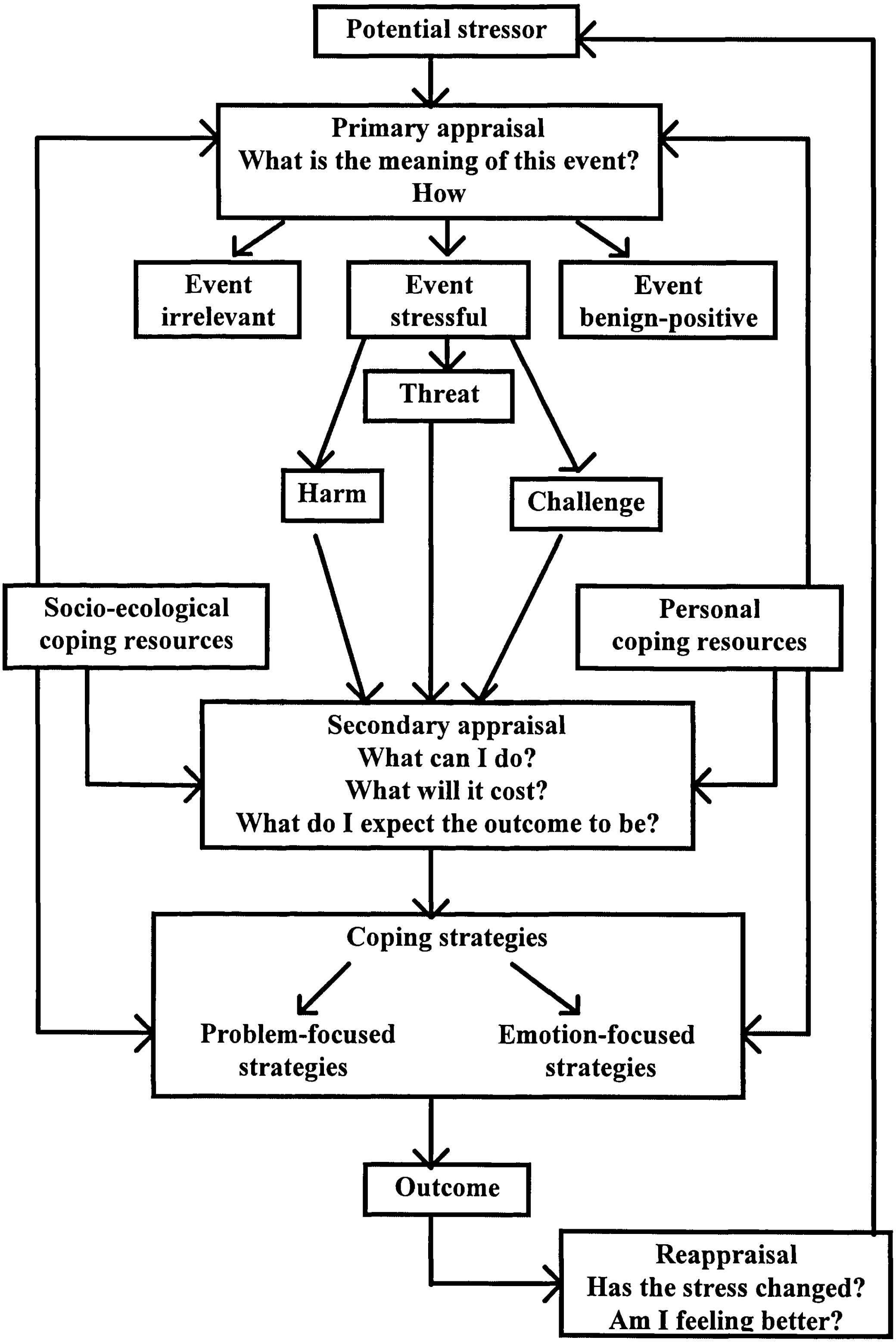


Fig. 1.1 The process model of stress and coping [Beresford, 1994]

1.9 The Theoretical Framework of the Process Model of Stress and Coping

The cognitive model of stress and coping is relational, contextual and process oriented (Folkman, 1984; Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986). The pivotal notion of this model is that the process of coping mediates the effects of stress on an individual's well-being. Coping is defined as "... the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p.283) and, thus, it is conceptualised as a process or ongoing complex interaction between an individual and his/her environment. Such, it views stress as the "relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering his or her well-being" (Folkman, 1984, p.840) and so nothing can be identified as a cause of stress independently of the relationship between the individual and the stressful encounter.

The model realistically views coping in relation to its management, as opposed to mastery, as it is recognises not every stressful encounter or event can be successfully mastered or resolved. The model makes no a priori assumptions about what constitutes good or bad coping: coping is defined simply as a person's efforts to manage demands, regardless of its success, and so independent of the outcome (Folkman & Lazarus, 1985). It emphasises the contextual nature of coping, that is, the coping style actually chosen is affected by the individual's appraisal of the actual demands of the stressful situation or encounter and the coping resources available for the mitigation of potential stressors.

Inherent in these key concepts is the importance of individual appraisal, that is, how phenomena are "perceived, interpreted and cognitively represented in the minds of the individuals" (Magnusson, 1982, p.231) determine whether events are appraised as stressful or not. There are two main cognitive appraisal processes: primary and secondary.

Primary appraisal involves making judgements about whether particular situations or events are irrelevant, benign-positive or stressful. An appraisal of an event as irrelevant signifies that it has no significance for well-being and a benign-positive appraisal shows that it does not tax or exceed the person's resources. Perceptions of harm, threat or challenge mean the event is appraised as stressful. Appraisals of harm or threat generate negative emotions, such as anger, fear, or resentment, whereas ones of challenge generate pleasurable emotions, such as excitement and eagerness. An appraisal of a stressful event is shaped by an array of personal and situational factors. Values, commitments, goals and beliefs about oneself and the world are among the important person factors that influence the appraisal of events in a given person-environment transaction and outcome efficacy.

The secondary appraisal consists of the individual evaluating what can be done about the stressful event and the efficacy of its outcome. This will partly depend upon the availability and utilisation of coping resources and coping strategies. Availability of resources affects the appraisal of the event (Redfield & Stone, 1979; Fong, 1991) and determines which coping strategies the individual employs. Examples of coping resources include physical (eg. health, energy, stamina); utilitarian (eg. finance, employment, housing); social (eg. social networks and support systems); and psychological (eg. belief systems, problem solving skills, personality). The primary and secondary appraisals converge to shape the meaning of stressful events and their perceived efficacy.

Coping can be understood in this model to have two prime functions: the regulation of emotions or distress using emotion-focused coping strategies and the management of the problem that is causing the distress using problem-focused coping strategies. Emotion-focused coping serves to ease painful or distressing emotions resulting from the stressor. The coping action is directed at the somatic level (eg. having a long hot bath, smoking a cigarette, taking a tranquilliser, going out for a walk) or emotional level (eg. watching a comedy programme, reading an amusing book, having fun with friends). Problem-focused coping serves to alter the "trouble person-environment relation causing the distress" (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986, p.993). The coping effort can be directed internally (eg. cognitive restructuring and mentally disrupting irrational beliefs) or externally (eg. negotiating to resolve an inter-personal conflict, taking a painkiller, asking for practical help).

Coping thus entails the mobilisation of effort that includes both "cognitive and behavioural efforts to manage (reduce, minimise, master or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources" (Folkman, Lazarus, Gruen & DeLongis, 1986, p.572). It is seen as the behaviour, cognitions or perceptions directed at resolution or mitigation of potentially stressful events. The outcome of coping may be positive or negative and can be reflected in physical or mental health and well-being. Outcome measure in studies of individual coping and stress has been predominantly negative (Dohrenwend, Dohrenwend, Dodson & Shrout, 1984; Quine & Pahl, 1985), but lack of distress is not a sufficient measure of successful adjustment (Sloper *et al*, 1991).

1.10 The Application of the Stress and Coping Paradigm in Research Practice

The following discussion of the application of the stress and coping paradigm in research practice will focus on research studies which have clarified the relationship between coping resources, coping strategies and outcomes in relation to carers and families of people with learning disabilities including challenging behaviour. Given that Lazarus' model has not been specifically used to examine the relationships between challenging behaviour as a potential stressor, coping resources, coping strategies and outcomes, the studies reviewed in this section will draw upon the findings of research conducted on carers of people with learning disabilities as well as specific types of disabilities and diagnostic categories. Due to the lack of research studies on carers of adults with learning disabilities, I will also draw upon the research findings based on children and adolescents.

This review of research outcome will primarily focus on those aspects of Lazarus' model that are pertinent to the questions that this study sets out to address in relation to parental primary caregivers of adults with challenging behaviour, and thus particular attention will be paid to the variables that are actually used. The following discussion of the issues pertinent to the study can be aided by the use of the summary illustration presented in Figure 1.2 as well as referring to the diagrammatic presentation in Figure 1.1.

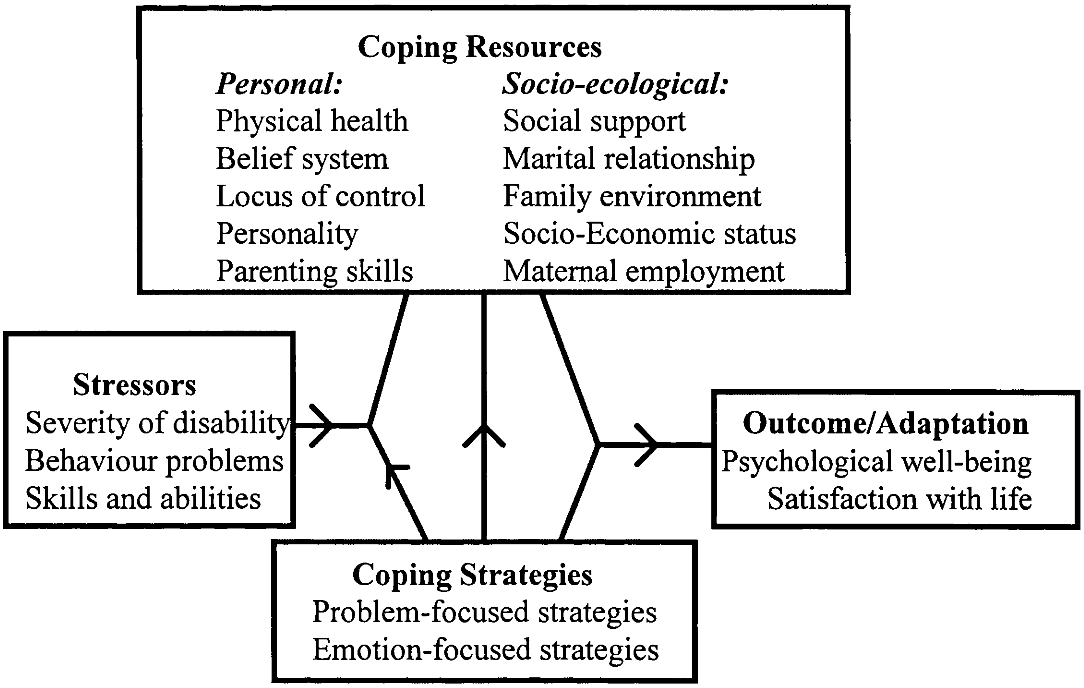


Figure 1.2 Composite model of stress and coping (adapted from McConachie, 1994)

Psychological Adaptation in Caregivers

Studies assessing parental distress or adaptation in studies of individual coping and stress have generally measured outcome in terms of physical and mental health using such measures as the Malaise Inventory (Rutter *et al*, 1970), the Questionnaire on Resources and Stress (QRS-F short form: Friedrich, Greenberg & Crnic, 1983) or General Health Questionnaire (Goldberg, 1978). Scores on these measures are taken as indicators of adaptation to the demands of caring for a person with a disability, with low scores being associated with good adjustment, and an absence of psychopathology is perceived as a positive outcome, although a lack of distress is not a sufficient measure of successful adjustment (Sloper *et al*, 1991).

Outcome measures used in research studies have been predominantly negative, with only a handful of studies having utilised measures of positive well-being such as the Mental Health Inventory (Veit & Ware, 1983). The impact of disability on parents' lives has also been assessed by a few researchers, such as perceived satisfaction with life (Sloper *et al*, 1991) and impact upon their social activities (Meltzler, Smyth & Robus, 1989; Wallander, Varni, Babani, DeHaan, Wilcox & Banis, 1989).

Meltzler *et al* (1989), surveying parents caring for a person with a disability, found that the physical and mental health of 37% of mothers was adversely affected. The findings of other research studies are similar and consistent, with parents of children with disabilities, including problem behaviour, scoring higher on health measures than parents of children without disabilities (eg. Bradshaw & Lawton, 1978; Quine & Pahl, 1986).

Disability-Related Chronic Stressors

Disability-related stressors include medical problems (eg. epilepsy), severity of learning disability (eg. communication or self-help skills), other disabilities (eg. visual, hearing, physical), problem and/or challenging behaviours (eg. incontinence, aggression, temper tantrums). These variables have been frequently shown in multivariate analyses to predict poor outcome for parental carers of people with disabilities (eg. Sloper *et al*, 1991; Quine & Pahl, 1985), mainly children and adolescents. Results vary from study to study, for instance, problem or challenging behaviours may be more significant in studies of learning disabled children in middle childhood (eg. Sloper *et al*, 1991) than young physically disabled children (Sloper & Turner, 1991), but very little is known about the influence of challenging behaviour in adults with learning disabilities in determining parental outcome or adaptation.

Coping with controllable stressors requires different coping strategies from managing uncontrollable stressors. For example, problem-focused coping styles are appropriate to manage a controllable stress (eg. an over-tired person using overnight respite care for their disabled son/daughter). If the stressor is uncontrollable, then emotion-focused coping may be more effective (eg. focusing on the self-help skills as opposed to the communication skills of learning disabled person). The nature of the stressor thus affects the choice of the coping strategy used, which means that research studies need to identify both the stressor and the coping strategy used to mitigate it in order to establish how effectively an individual is coping (Summers, 1988). Yet research literature examining the effectiveness of different coping strategies in response to the specific stressor of nature and severity of challenging behaviour in adults with learning disabilities on parental primary caregivers and their families is extremely lacking in this field.

Coping resources as mediators of the stress-adjustment relation

Given that coping resources mediate the ways individuals appraise potential stressors, and the options that are available for choice of coping strategy, they can be conceived of as both protective and risk factors in relation to resistance and vulnerability to stress (Sloper & Knussen, 1991). Both personal and socio-ecological coping resources have been shown to significantly account for variance in physical and mental health (eg. Cobb, 1976).

Personal coping resources

Personal coping resources (physical health, morale, ideological beliefs, previous coping experiences, parenting skills, intelligence and personality characteristics) have been found to be important coping resources for parents of a disabled person

(Beresford, 1994). Parental physical health is an important coping resource (Brown & Hepple, 1989) but tends to be used as an outcome variable in most research studies. Caring can be physically tiring and/or result in lack of sleep, which can test parents' endurance and energy levels (Quine & Wade, 1991). Chronic fatigue is likely to deprive parents of quality 'time out' with partners and friends (Gough, Li & Wroblewska, 1993).

Religious or ideological belief systems have also been shown to be important resources to parents caring for a disabled person (Beresford, 1994), especially beliefs which offer explanations about the event of a child being disabled, beliefs in the efficacy of prayer, and beliefs about being given the strength to cope (Fewell, 1986). However, the findings are equivocal for parents of children with disabilities (Byrne & Cunningham, 1985), which maybe due to the ambiguous way that religiosity has been conceptualised and used as both a personal and socio-ecological resource factor interchangeably by researchers.

Research into the impact of personality traits on the coping processes of parents with a disabled child shows that personality variables are not only important coping resources in themselves, but they also affect the availability of other personal and socio-ecological coping resources (Sloper *et al*, 1991). McCrae & Costa (1986) and Bolger (1990) found that individuals with high neuroticism scores were more likely to use wishful thinking and self-blame coping strategies than those with low neuroticism scores. Sloper *et al* (1991), in families of Down's Syndrome, found neuroticism scores were a significant predictor of mothers' and fathers' perceived satisfaction with life and their mental and physical health, and have further suggested that neuroticism "reflected characteristics which make a person vulnerable to stressful reactions" (p.668).

Research has shown that locus of control beliefs predict mothers' perceptions of disability-related stressors. Friedrich *et al* (1985) and Frey, Greenberg & Fewell (1989) found mothers with internal locus of control beliefs perceived fewer difficulties associated with the disabled child than those with external beliefs. Overall, such findings suggest that internal locus of control beliefs appear to be more adaptive than external beliefs, although there are exceptions. For instance, Affleck, Allen, Tennen, McGrade & Ratzan (1985) showed that parents who had external locus of control beliefs about the cause of chronic illness in their children enabled them to successfully adapt to the illness and its management. As with personality variables, the nature of the relationship between locus of control, coping and adjustment is not always a direct one, and there is evidence suggesting that locus of control beliefs interact with other coping resources, such as social support (eg. Dean & Ensel, 1982; Sandler & Lakey, 1982; Lefcourt, 1985), to affect the coping process (eg. Knussen & Cunningham, 1988).

Increasing parents' skills and competencies in dealing with behaviour problems has been found not only to have the effect of reducing behavioural difficulties (Moran & Whitman, 1991; Quine & Wade, 1991), but it also enhances parents' general sense of competence in relation to caring for their sons and daughters. Research studies have found this to be consequently associated with reduced levels of stress in parents, regardless of the extent of improvements in the child's behaviour (Pisterman, Firestone, McGrath, Goodman, Webster, Mallory & Goffin, 1992).

Socio-ecological coping resources

Socio-economic coping resources (marital relationship, social networks, practical or functional resources and economic circumstances) have also been found to act as risk and resistance factors to an individual's adjustment (Beresford, 1994). Social support has been found to be an important coping resource in families with a disabled child (eg. Venters, 1981; Sherman & Cocozza, 1984; Dunst, Trivette & Cross, 1986). Bristol (1979) found, amongst mothers of children with autism, an association between the degree of available social support and parental and family stress.

Social support affects the ways parents are able to cope through the functions it serves including emotional and moral support, information, or practical help (Barrera & Ainlay, 1983). Social support is derived from three main sources: intimately, from family members and close friends; less informally, from neighbours or distant friends; and more formally, from professional agencies and workers (Schilling, Gilchirst & Schinke, 1984).

Social support has been conceptualised and measured in a number of different ways (Eckenrode, 1983; Barrera, 1986; Lin, Dean & Ensel, 1981; Vaux & Harrison, 1985; Veiel, 1985). However, in a review of existing of literature, Beresford (1994) concludes that it is perhaps more helpful and meaningful to measure parents' perceptions of social support resources available to them, which is the orientation taken in the present study.

Spouse support and marital status are conceived as two distinct coping resources. A number of research findings suggest that marital status per se is an important coping resource in mediating stress (Wallander, Pitt & Mellins, 1990; Lawton, 1992). Sloper and Knussen (1991) found that spouse support was related to positive outcome in both mothers and fathers. Findings suggest spouse support is the most important form of support to parental caregivers (eg. Holroyd, 1974; Barbarin, Hughes & Chesler, 1985; McKinney & Peterson, 1987; Byrne *et al*, 1988). Marital satisfaction and availability of support have been found to be positively associated with maternal adaptation (eg. Bradshaw & Lawton, 1978; Gallagher, Cross & Scharfman, 1981; Friedrich, Wilturner & Cohen, 1985) and a significant predictor of coping behaviour (Friedrich, 1979).

The nature of the family environment has been shown to make families more resistant to crisis and more able to adapt to crises (Olson *et al*, 1979; McCubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980; Nihira, Meyers & Mink, 1980). Quine & Pahl (1991) found that a "tense home atmosphere" was positively associated with poor maternal physical and mental health. Sloper *et al* (1991) found an association between mothers' and fathers' perceived life satisfaction, mental and physical health and the family environment. In the univariate analysis of their data, Sloper *et al* (1991) found that measures of family cohesion, family expression and family conflict were associated with the outcome measures for both parents. A high degree of family conflict was negatively associated with good outcome, and high levels of family cohesion and family expression were positively associated with good scores on the outcome measures.

Socio-economic circumstances have been found to be a fundamental source of stress in families with a disabled child (Dyson, 1991) ranging from worries about money to the strain of living in poor housing conditions (Bradshaw & Lawton, 1978). A number of studies of families with disabled children have found high levels of stress to be associated with deprivation (eg. Kazak & Marvin, 1984; Quine & Pahl, 1985; Dunst *et al*, 1986; Quine & Pahl, 1989; Sloper & Turner, 1993). Maternal employment is also an important variable in predicting the well-being of mothers with disabled children (Cooke, 1982; Hirst, 1984), although Bristol (1984) found this was more dependent upon mothers' satisfaction with their employment status (Bristol, 1979) rather than employment per se.

Coping strategies and parental caregivers' health and well-being

Comparatively little research has been conducted on examining the relationship between the use of coping strategies and parents' health and well-being in relation to caring for a son/daughter with a disability. Much of the existing literature in this area has been relatively recent and, in general, is firmly embedded in the process model of stress and coping (Lazarus, 1966). These research studies have typically adopted a multivariate correlational standpoint to investigate the relationships between potential stressors, coping resources, coping strategies and psychological adjustment. Examples of these studies were discussed at some length when reviewing the literature, so only the main findings will be briefly summarised here to illustrate the nature of the relationship between coping strategies and health adaptation in parental caregivers.

Quine & Pahl's (1985) findings suggest that coping is a more significant determinant of maternal health and well-being than the severity of the stressors, for example, behaviour problems, being encountered. Sloper *et al* (1991) suggest that different coping strategies affect different aspects of maternal adjustment and recommended the use of more than one measure of outcome or adaptation. For example, they found that practical coping significantly predicted mother's perceived satisfaction with life, but wishful thinking was a significant predictor of poor mental and physical health. Frey, *et al* (1989), in exploring coping in parents of physically or learning disabled children, found that parents who used problem-focused coping strategies experienced less parenting stress and less psychological distress, and seeking social support was associated with less psychological distress in mothers. Their study showed the use of three types of coping strategy were associated with poor outcome scores: avoidance coping and wishful thinking in mothers and fathers as well as mothers who blamed themselves for their child's disability.

In a study undertaken on the parents and families of young adults with learning disabilities and challenging behaviour living in their parental home, Kiernan & Alborz (1995) found that mothers who favoured passive acceptance or wishful thinking as preferred coping strategies were likely to report poor physical and mental health, but those mothers who had a tendency to use stoicism as an approach to coping were more likely to feel that their general health was good. Clearly, research evidence consistently suggests that parents with poor adjustment scores use more palliative coping strategies than parents with good adjustment scores. In spite of this, however, the existing knowledge base is far from complete, and there is an urgent demand for the results of research studies examining the multivariate relationships between coping strategies and the health and well-being of parental primary carers of adults with learning disabilities and challenging behaviour living at their parental home.

Conceptualising the role of coping strategies

Lazarus and his colleagues developed the Ways of Coping instrument (Folkman &

Lazarus, 1980), which has since been revised (Folkman & Lazarus, 1985), to investigate the process of coping. Inherent in this scale is a distinction between two general types of coping styles: problem-focused coping and emotion-focused coping. Most stressors elicit both types of coping, but problem-focused coping tends to predominate when people feel that something constructive can be done, whereas emotion-focused coping tends to prevail when people feel that the stressor must be tolerated (Folkman & Lazarus, 1980).

The Ways of Coping measure has been heavily criticised by researchers because the distinction between problem-focused and emotion-focused coping, although an important one, has proven to be too simple, vague and ambiguous (Carver, Scheier & Weintraub, 1989). Several studies have found that responses to the Ways of Coping scale form more than the two factors (eg. Aldwin, Folkman, Schaefer, Coyne & Lazarus, 1980; Folkman & Lazarus, 1985; Sloper *et al*, 1991), which makes it very difficult to compare studies. For instance, using the Ways of Coping scale, Knussen, Sloper, Cunningham & Turner (1992) got five factors: practical coping, wishful thinking, stoicism, seeking emotional and social support, and passive acceptance.

Carver *et al* (1989) describe two main problems with the Ways of Coping and similar coping instruments. They criticise the items of existing coping scales as lacking a clear focus or being ambiguous. In other words, items tend to describe a coping act without adequately indicating why it is being done, or conceptually distinct qualities may be combined in a single item. Secondly, no existing scale measures all the specific domains the authors feel are of theoretical interest because items have primarily been derived empirically rather than theoretically.

For example, in the Ways of Coping, some emotion-focused responses involve denial, whereas others involve positive reinterpretation of stressful events, and still others involve the seeking out of social support. These responses are very different from each other, and they may have very different implications for a person's success in coping in a stressful transaction (Scheier, Weintraub & Carver, 1986). Problem-focused coping can also involve several distinct activities: planning, taking direct action, seeking assistance, screening out other activities, and sometimes even forcing oneself to wait before acting. Drawing on both theoretical literature and empirical research findings, Carver *et al* (1989) argue there are several diverse and conceptually distinct coping styles, which have different implications in terms of a persons coping efficacy, and this diversity of potential coping responses need to be studied separately which, therefore, also requires ways to measure them separately (Scheier *et al*, 1986).

Based on this analysis and a critique of the Ways of Coping measure and other existing coping scales, Carver *et al* (1989) developed the COPE, a multi-dimensional coping inventory, to assess the different ways in which people cope with stress. It is a comprehensive self-report measure, comprised of thirteen theoretically and empirically derived sub-scales, reflecting the widely adopted view of coping as a multidimensional construct involving a wide range of cognitive and behavioural strategies which may be adaptive or maladaptive in dealing with a potential stressor.

The COPE (Carver *et al*, 1989) comprises 13 subscales, of four items each, which theoretically form five scales that measure conceptually distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support); five scales measure aspects of what might be viewed as emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measure coping responses that are arguably less useful (focus on and venting of emotions, behavioural disengagement, mental disengagement). The 13 coping sub-scales have also been grouped into three second order coping sub-scales including problem-focused coping, emotion-focused coping and the third sub-scale is more loosely defined as 'less adaptive coping'. The actual COPE instrument contains two additional, albeit exploratory subscales, using humour and drugs/alcohol as a style of coping with stressful events.

In practice, however, Carver and his colleagues (1989) found that a factor analysis of the 13 subscales of the COPE resulted in four clusters or second order factors, but did not further attempt to conceptualise or think about the underlying dimensions as to what these four factors were actually measuring. Factor one composed of active coping, planning and suppression of competing activities; factor two composed of seeking instrumental and emotional social support and focus on emotions; factor three composed of denial and both mental and behavioural disengagement; and factor four composed of acceptance, restraint coping, and positive reinterpretation and growth. Only turning to religion failed to load on any of these factors, and the subscales relating to the use of humour and alcohol/drugs subscales are the new additional, but still exploratory, components of the COPE.

Although Carver *et al* (1989) did not conceptualise these four second-order factors, factor one does appear to be measuring coping behaviours that can be more broadly defined as 'active planning and coping', factor two seems to be measuring 'seeking social support', factor three appears to entail 'active avoidance and denial' and factor four seems to refer to 'stoicism'. These are the definitions or conceptualisations that are to be used in the present study to refer to the four second-order COPE scales specified by Carver *et al* (1989). The individual subscales of the COPE are used in the descriptive part of the study, and the statistical analysis employs the four second order subscales, the turning to religion subscale and the two exploratory subscales, humour and alcohol/drugs.

1.11 The Basis for the Present Study

The existing literature on people with learning disabilities and challenging behaviour has tended to focus to a greater extent on their epidemiology or the practical demands and costs of caring (Qureshi, 1992; Qureshi, 1993; Kiernan & Alborz, 1995), rather than the parents' adaptation and psychological health and well-being. Other research studies in the field clearly show that carers of children with behaviour problems are more likely to suffer from stress (Quine & Pahl, 1985; Quine 1986; Margarit *et al*, 1989; Saxby & Morgan, 1993). However, a number of studies (Snowdon *et al*, 1994) contradicting these findings have recently made their way to the existing literature on challenging behaviour. For example, Snowdon *et al* (1994) report that social support from spouses and friends was related to satisfaction with family functioning in parental carers, although acknowledging behaviour problems are experienced as significant stressors. Several factors can account for these apparent contradictions: difficulties in operationalising the term "challenging behaviour"; adoption of mixed methodologies; researchers' biases or prejudices relating to the traditional and/or liberal based family models on the impact of disabilities on carers and their families, resulting in the use of differing methodologies and mixed research findings.

Nevertheless, it is clear from these studies that there is a wide variation in response between different carers and their families of people with similar types of challenging behaviour, yet this variation has only recently begun to be acknowledged in the field of disabilities as has the investigation of factors that may be related to it (Kiernan & Alborz, 1995). Such investigation can identify factors which may place families at risk for stress or poor functioning, and conversely, those which may act as protective factors providing resistance against such stress. Research studies which can identify such risk and resistance factors are lacking in the literature on general disability, but are extremely scant on carers and families of people, especially adults, with challenging behaviour. There are several reasons for this.

Many studies (eg. Sloper *et al*, 1991) focus on a single diagnostic category, such as Down's syndrome, or autism, and thus their findings cannot be generalised to the general population of people with learning disabilities and challenging behaviour. Where studies have attended to the needs of carers and families of people with problematic behaviours, the samples tend to be restricted to children or adolescents or young adulthood. In most cases, where sample sizes are small, it is not possible to identify the needs and problems of carers of challenging behaviour, unless done qualitatively, which studies have done so (Hubert, 1991; Qureshi, 1993; Kiernan & Alborz, 1995). However, this chapter has highlighted that the psycho-social-cognitive needs of carers and families of people who show challenging behaviour are not only likely to differ from those caring for people with particular disabilities or diagnoses but are also likely to show variations amongst them. Yet little attention has been given to the investigation of such differences, despite the fact that information on the specific needs of carers and families of adults with challenging behaviour is necessary to inform policy and service delivery.

Few studies have investigated the wide range of variables that may be associated with parental primary caregiver adaptation. Measurement has tended to be confined to demographic variables and characteristics of the child, such as behaviour problems or degree of impairment. Again, the literature presents conflicting findings on the relationships of these variables to family adaptation. The use of univariate methods of statistical analysis can fail to delineate the independent or interactive contributions of different variables, as Quine & Pahl's (1985) study showed problematic behaviours were clearly a cause of stress. However, Bradshaw and Lawton's (1978) study, using multivariate analysis, showed the relatively small contribution to the variance in maternal stress scores of such variables, and found that factors internal to the mother, such as personality, were apparently more important. Despite these observations, few studies have attempted to measure or control for such factors.

In the field of learning disability and mainstream work on stress, it has been shown that a number of studies have addressed a wider range of variables and their relationship to family adaptation, stress and quality of life (eg. Crnic *et al,* 1983; Friedrich *et al*, 1985; Sloper *et al*, 1991). These studies suggest that family resources, ways of coping, personality, life events and social support are all influential variables.

In the field of challenging behaviour such broad ranging multivariable studies are rare. Recently the work of Kiernan & Alborz (1995) has applied the model of stress and coping to the study of adaptation in mothers of young adults with challenging behaviour. Their work has highlighted the importance of psychosocial stress and resource factors in maternal adaptation and the lack of effects of characteristics, such as degree of impairment and behaviour. However, the small sample upon which their study is based and the restricted age range limits the generalisability of their findings.

Families of people with challenging behaviour often require a complex range of services encompassing a variety of professional disciplines. It can be a difficult task for parents to obtain access to a comprehensive package of services in order to meet their own and their child's needs. The increasing emphasis on community care and the evidence that, for adults with challenging behaviour, this is primarily family care, with the main burden often falling on the mother (Romans-Clarkson *et al*, 1986), points to the importance of examining the professional and service needs of parents and families to meet their needs and relieve the stress of caring. These issues form the basis of the present study.

1.12 The Perspective of the Present Study

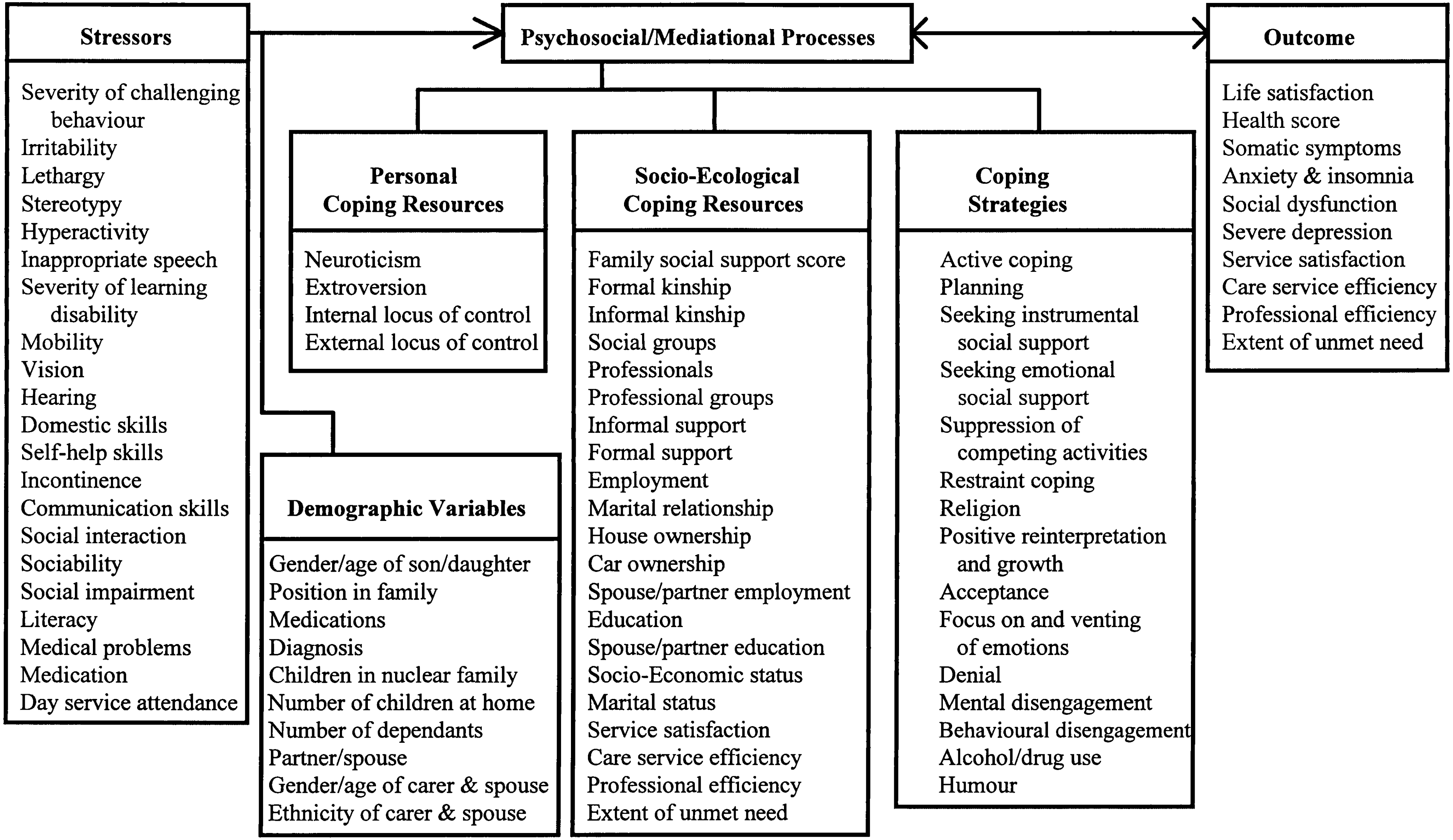
A comprehensive review of the relevant literature has clearly illustrated that barely any research studies have applied a conceptual framework of stress and coping, one that is both theoretically and empirically sound, to investigate the psycho-social-cognitive impact on carers and families of adults with learning disabilities and challenging behaviour. Also, existing research studies do not seem to portray an adequate understanding of how particular stressors, coping strategies, psychosocial adjustment and quality of life of parental primary carers of people interrelate with each other as well as their views, needs and experiences of professional services.

The present study examines these scantily researched issues relating to stress, coping and adjustment in parental primary caregivers of adults with challenging behaviour. It specifically adopts the following standpoint as its primary focal theme.

- Development of a specific model of stress and coping for parental primary caregivers in relation to caring for an adult with learning disabilities and challenging behaviour. Further, based on previous research, the following are the questions and underlying themes that the study sets itself the task of addressing:
  (I) What are the types of stressors in parental primary caregivers?
  (II) What are the coping resources of parental primary caregivers?
  (III) What coping strategies are used by parental primary caregivers?
  (IV) What are the levels of stress and life satisfaction in parental primary caregivers?

The potential stressors to be studied are the challenging behaviour of the adults with the learning disability as well as various characteristics relating to the disability itself. Additionally, demographic information will be gathered about the parental caregivers, their partner/spouse and family. Coping resources, both personal and socio-ecological, and coping strategies of the parental caregiver will also be examined. Outcome variables will focus on parental adaptation, which will be assessed by primary caregivers' health and well-being as well as their perceived satisfaction with life. The depicted stress and coping model for parental primary carers of people with challenging behaviour is illustrated in Fig 1.3, which has been specifically adapted from Thompson *et al* (1992) to include the measures and variables used in the present study.

Fig. 1.3 The depicted stress and coping model applied to parental primary carers of adults with challenging behaviour (Adapted from Thompson, Gustafon, Hamlett & Spock, 1992)



- Additional qualitative data on parental primary caregivers to explore their views, experiences and needs of services. This is diagrammatically presented in Figure 1.4.

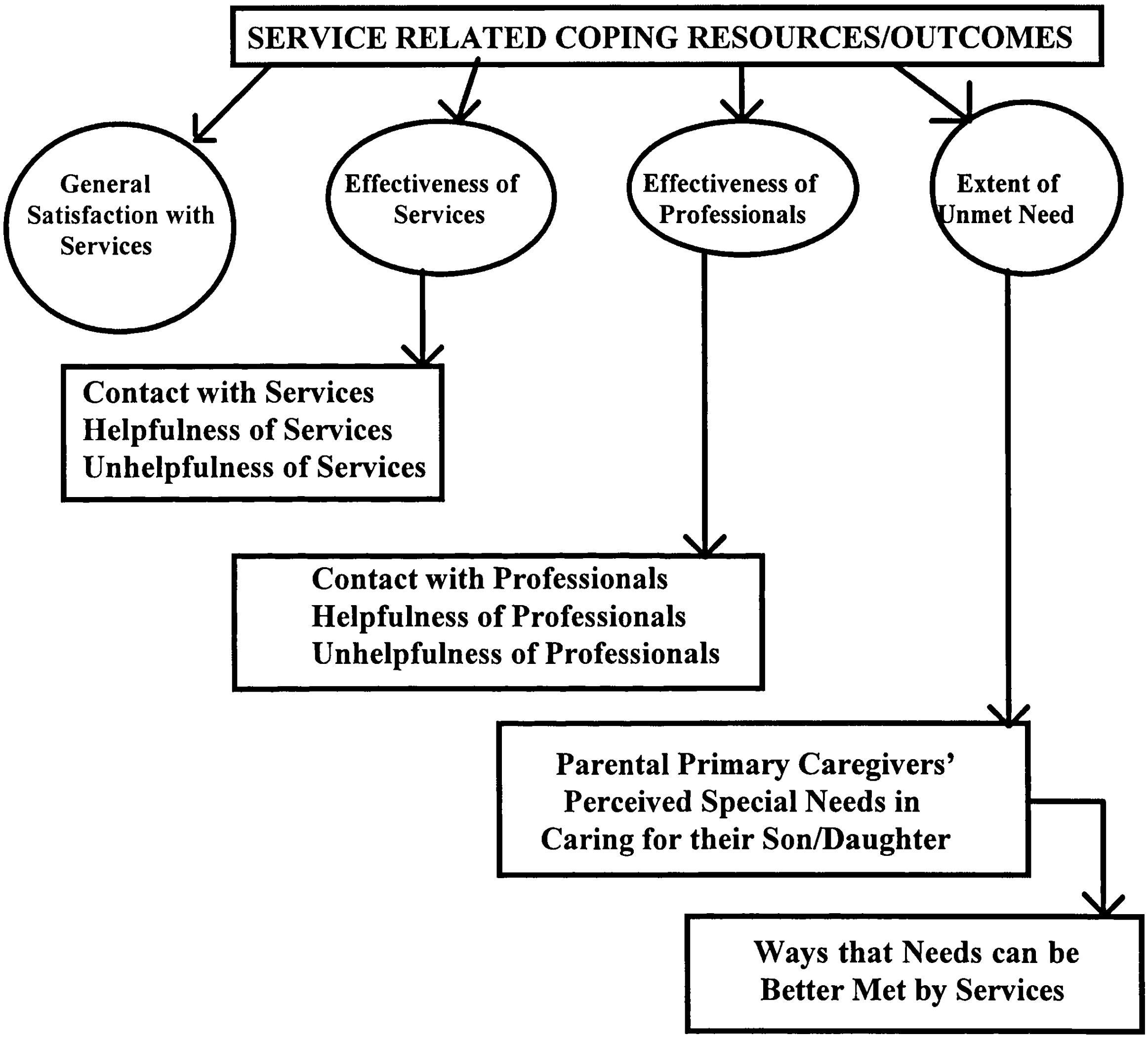


Figure 1.4 **Diagrammatic illustration of caregivers' experiences, views and needs relating to services for people with challenging behaviour**

The quantitative variables used in the depicted stress and coping model (Figure 1.3) will be linked with the service-related ratings and an exploration of caregivers' perceptions, needs and experiences relating to professional services (Figure 1.4). Each aspect of the study informs the other, and so the two parts of the study act like a feedback loop, as illustrated by the linkage between the service related coping resources in Figure 1.4 and socio-ecological coping resources in Figure 1.3. Due to the transactional nature of the stress and coping model (Byrne & Cunningham, 1985), the service related information can also be treated as outcome measures (Figure 1.4) in a similar way to psychological well-being and life satisfaction (Figure 1.3), that is, a statistical analysis of the four service-related scores can be undertaken to see how they are related to potential stressors, resources and coping strategies of parental primary caregivers. Combining these aspects of the study in this way enables the elaboration of a much richer and detailed picture of the impact of challenging behaviour on parental primary caregivers and their families.

1.13 Research Questions and Hypotheses

RESEARCH QUESTIONS

Q1 What are the inter-relationships between potential stressors (challenging behaviour, severity of learning disability, skills and abilities), internal (personality traits, locus of control and attributions of challenging behaviour) and external (social support, marital satisfaction, employment, education, socio-economic status, car and home ownership) coping resources, coping strategies (emotion-focused and problem-focused) and psychosocial adaptation (satisfaction with life, psychological health and well-being, satisfaction with service delivery) in parental primary carers of adults with challenging behaviour?

Q2 What are parental primary caregivers' views, experiences and needs relating to services?

HYPOTHESES

H_1 The severity of challenging behaviour will be correlated with psychosocial adaptation in parental primary caregivers, with higher levels of behaviours being associated with poorer functioning in terms of psychological health and well-being, perceived satisfaction with life and efficacy of service delivery.

H_2 Personal and socio-ecological resources will moderate or mediate the effects of challenging behaviour on parental primary caregivers' psychosocial adaptation by providing resources at both the primary and secondary appraisal stages of the coping process. The presence of resource variables can be viewed as acting as resistance factors and increase the likelihood of adaptive psychosocial adjustment, whereby the lack of a resource may increase the likelihood of maladaptive psychosocial adjustment. The number and availability of coping resources are likely to be associated with better outcome or higher levels of psychological health and well-being, perceived satisfaction with life and efficacy of service delivery.

H_3 The range of coping strategies used by parental primary caregivers to cope with the challenging behaviour exhibited by their sons/daughters will be predictive of psychosocial outcome. The greater use of maladaptive coping strategies is likely to be associated with lower levels of psychological health, adjustment and well-being, perceived satisfaction with and efficacy of service delivery, whereas the greater use of adaptive coping strategies is likely to be associated with higher levels of psychological health, adjustment and well-being.

1.14 Aims and Objectives

The broad aim of the present study is to gain a better understanding of the impact of challenging behaviour on parental primary caregivers and their families. It aims to develop a specific process model of stress and coping for parental primary carers of adults with learning disabilities and challenging behaviour. It is hoped that such an impact model of challenging behaviour will enable clinicians and services to better understand the needs of parental primary caregivers and their families and thus meet the needs of this client group more effectively. The main objective is to facilitate a shift in the focus of work in services to prevention as opposed to crisis management.

The study further aims to provide a better insight into the nature and type of stressors, resources, coping strategies and quality of life of parental primary carers of adults with learning disabilities and challenging behaviour. It will attempt to identify risk and protective factors related to relatively good or problematic adjustment and functioning in caregivers. From this, it will try to map out the pathways by which a variety of psychosocial factors may contribute to good or poor adjustment in caregivers. It hopes this information will enable clinicians to identify at-risk families and their needs for early intervention to reduce the risk of problems and their subsequent familial impact.

The study also aims to explore caregivers' views, experiences and needs relating to professional services. It will examine patterns of service use, levels of satisfaction, the nature of caregivers' needs in relation to caring for their sons/daughters and their perceptions of existing gaps and limitations in service delivery and organisation. It is hoped that this information will be used by services to provide more effective, appropriate and individually tailored support for such families.

CHAPTER TWO

Methodology

2.1 Design

In order to gain an understanding of the psychological impact, both social and cognitive, of challenging behaviour on parental primary caregivers, as explored and examined in the previous chapter, a cross-sectional, correlational design was used involving the administration of self-report questionnaires and the conduction of a semi-structured interview with parental primary caregivers. This particular design was chosen by the researcher because the practical and resource limitations imposed on the study ruled out the use of a longitudinal design.

A major limitation of the use of a cross-sectional, correlational design is that it does not allow any conclusions to be drawn about causal direction, for example, whether better coping strategies arise from better personal resources or vice versa. Nevertheless, the use of a correlational design does permit the use of simple statistical measures of association as well as multivariate methods, thus enabling potential within-group individual differences to be uncovered. More specifically, the intercorrelations among descriptor variables can be investigated, as well as the combination of variables most strongly related to positive and negative outcomes in terms of life satisfaction and health.

2.2 Participants

Four hundred and twenty families were contacted and invited to participate in the study via the referral agents who sent all parental caregivers a service cover letter (see Appendix 6), a participant information letter (see Appendix 7), and a reply return slip (see Appendix 8) to indicate their decision, either way, using the stamped self-addressed enveloped provided to them for their reply. 132 families returned the blue consent slip with 55 families declining to take part and 76 families agreeing to take part. Three families gave reasons as to why it was difficult to participate, namely, because they had moved house, lack of time and energy, or they did not meet the study criterion. However, 13 of the remaining families were later excluded from the study because they proved not to fulfil the selection criterion for the study, usually because the adult with the learning disability was no longer living at his/her parental home or they did not have show challenging behaviour.

Two families had to be excluded because they responded after the scheduled date for data collection. 4 families withdrew from the study prior to conducting the semi-structured interview. These 4 families withdrew their consent following receipt of the self-report questionnaires because they found the questionnaire had been administered before, had more than one son/daughter with a disability and wanted both to be included in study although only one actually met the selection criterion, felt the study's questions were inappropriate to their son/daughter with the learning disability, or because one caregiver had lost her completed questionnaire and time did not permit her to do another one. 4 families fulfilled the study criteria but had to be excluded because the parental primary caregiver could not speak fluent English.

The final sample comprised of 54 **parental primary caregivers** in families containing an **adult** with a learning disability and exhibiting **challenging behaviour**, using the above defined selection criterion for participation in the study. 52 primary caregivers were successfully interviewed and 54 completed the questionnaires, as 2 families were unable to fully complete the semi-structured interview due to shortage of time and energy.

Inherent in such a sample size, given that only approximately 13% of the parental primary caregivers in the identified 420 families containing an adult member with a learning disability and exhibiting challenging behaviour were interviewed, are inevitable biases that need to borne in mind when interpreting the results of the statistical analysis. However, although there were clearly some cultural biases in the final sample interviewed, the unavailability of background information on those families who did not actually take part in the study made it very difficult to determine other possible biases.

Parental Primary Caregiver is defined as the person in the family who accepts the main responsibility for providing care for the adult who has a learning disability and exhibits challenging behaviour.

An ***adult*** is defined as the person with the learning disability falling in the 18 and over age range.

Challenging Behaviour refers to "behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary facilities" (Emerson, Barrett, Bell, Cummings, McCool, Toogood & Mansell, 1987). This definition is based on the Department of Health funded research at learning disability research establishments at the Universities of Kent, Manchester and

Cardiff. This definition was used to identify the presence of challenging behaviour in adults with learning disabilities living at home with their families. It refers to behaviour that falls into one or more of the following categories: ***aggressive*** (eg. hitting, kicking, biting, pinching, spitting, pushing, scratching, pulling hair, grabbing); ***self-injurious*** (eg. hitting, slapping, punching, pinching, poking, pulling hair, scratching, biting); ***destructive*** (eg. deliberately throwing, sweeping or breaking objects); ***disruptive*** (eg. vocalising, screaming, shouting, crying, lying on floor, wetting self with awareness in place other than toilet, smearing, non-compliance, banging, spitting); and ***stereotyped*** (eg. repetitive spinning, running, object glazing, climbing, body rocking, hand and body movements). Furthermore, the extent and nature of the challenging behaviour exhibited by the adult with the learning disability was quantitatively rated by all the parental primary caregivers using the Aberrant Behaviour Checklist - Community (Aman, Singh, Stewart & Field, 1985a; 1985b).

42 (78%) parental primary carers were mothers and 12 (22%) were fathers. 8 (15%) families were headed by a lone parent, all mothers. 45 (83%) of parental primary caregivers were married, 4 (7%) divorced, 2 (4%) widowed, 2(4%) separated and 1 (2%) single. The social class distribution of the sample, based on current or last occupation of the head of the household, was compared with national statistics (OPCS, 1987), and is given in Table 2.1.

Table 2.1 Social class distribution

	I	II	III (non-manual)	III (manual)	IV	V
Study Sample[a]	7%	37%	14%	33%	9%	0%
1985 National Figures[b]	7%	21%	17%	38%	13%	4%

[a] Based on Registrar General Classification of Occupations (OPCS, 1980) for father's present occupation where currently employed, last occupation where currently unemployed, and mother's current or last occupation if single parent mother.
[b] For economically active males aged 25-64.

2 (4%) primary caregivers were the foster parents of the adult with the learning disability, 6 (11%) adoptive parents, 1 (2%) step-parents and 45 (83%) were natural parents. In 12 (22%) the parental primary caregiver was working full time, 8 (15%) worked part-time, 12 (22%) were retired and 22 (41%) were not employed, considering their role as full time caregivers. 46 (85%) of parental primary caregivers described their ethnic status as white and 8 (15%) as non-white, the latter falling into the following categories: 1 was Jewish, 1 was Anglo-Burmese, 4 Indian, 1 Afro-Caribbean and 1 Mixed: White & Afro-Caribbean.

The mean primary parental caregiver's age was 55 years (range 43-73); mean age of spouse/partner was 59 years (range 42-76); mean age of adult with learning disability was 26 years (range 18-43). Thirty (56%) of the adults with the learning disability were male and 24 (44%) female. Ten (19%) of adults with disabilities had no siblings, 15 (28%) had one sibling, 17 (32%) had two siblings, 12 (21%) had at least three siblings. Out of those adults who had other siblings, 30 (56%) had at least one sibling still living at home. Ten (19%) of adults were only children, 3 (6%) took middle position in family, 17 (32%) were the eldest, 20 (37%) the youngest, and 4 (7%) in a "multiple" position.

Twenty-six adults were on no psychotropic medication and the other 28 were on at least one psychotropic medication. Twenty nine adults had no other medical problems and 23 had at least one other medical problem. Table 2.2 gives a range of medical conditions in the adults with learning disabilities and Table 2.3 gives a range of the diagnostic labels given to them by their families.

Table 2.2 Medical conditions in adults with learning disabilities

Medical Condition	Number
Epilepsy	13
Hayfever	4
Asthma	3
Diabetes	2
Hypothyroidism	1
Anorexia Nervosa	1
Dry skin - ichthyosis	1
Distorted hip	1
Rashes - genital area	1
Athletes' foot	1
Lymph swalomas	1
Neurofibromatosis	1
Stomach ulcer	1
Eating disorder	1
Clinical depression	1
Hernia - fibroids	1
Lazy bowels	1
Haematoma	1
Stammering	1

Table 2.3 Diagnosis in adults with learning disabilities

Diagnosis	Number
No diagnosis	20
Autism	9
Down's Syndrome	6
Recessive micro cephelo (small brain)	5
Asperger's Syndrome	3
Brain damage	2
Autism/Cerebral palsy/Aphatoid//Scoliosis	1
Hydrocephalus	1
Cerebral palsy	1
Anterior Horn's Disease/Arrested hydrochophallic	1
Prada Willi Syndrome	1
Meningitis - brain damage	1
Tuberous sclerosis	1
Low lobe epilepsy	1
Angel Man Syndrome (Happy Puppet Syndrome)	1

2.3 Materials

The choice of data collection methods in the present study was informed by its aims and objectives as well as a review of the relevant literature. Much of the available literature on family and parental functioning is based on the use of standard measures, which indicate that important variables of stress, adaptation, locus of control, social support and coping styles can be quantitatively collected from parental primary caregivers. Thus, the use of such measures in the self-report questionnaires allowed an economical method of data collection, whilst providing comparability with other studies. However, it was felt that this method alone would not allow parental primary caregivers to freely express their views and may also miss material relating to Learning Disability Services which may be of particular relevance and importance to these families. Thus, in the more descriptive and exploratory areas of the study, more qualitative data was required. These areas were concerned with individuals' experiences and views of care services and professional input. Thus, the semi-structured interview was chosen as a method for these more qualitative and exploratory aspects of the study.

Data were collected using self-report questionnaires (see Appendix 10) and a semi-structured interview schedule (see Appendix 12) with parental primary caregivers, usually mothers and occasionally fathers. The booklet of self-report questionnaires asked questions about their health, satisfaction with life, personal attitudes and traits, family and social relationships, coping styles and the nature and severity of challenging behaviour in their sons/daughters with the learning disability. At the actual interview appointment, the researcher asked participants questions about their personal and family background, based on Part I of the semi-structured interview schedule, as well as their son/daughter with the learning disability and his/her behaviour, based on Parts II and III of the semi-structured schedule. Caregivers' personal views, needs and experiences relating to Learning Disability Services were explored using Part IV of the semi-structured schedule. Part IV constituted the tape-recorded interview.

The questions asked by the research study were selected very carefully, primarily directed or guided by the theoretical model of family adaptation. Despite the detailed self-report questionnaires, only a few characteristics were actually being measured (eg. psychological well-being, coping strategies used, marital satisfaction). All variables had been associated with levels of stress in carers of people with learning disabilities in previous research. Requests for irrelevant information were removed at a very much earlier point in the design of the study. These relevant variables were measured using established, standardised self-report questionnaire scales, with demonstrated reliability and validity, and used in previous research studies. A summary of the outcome and descriptor variables is given in Table 2.1 below. Details of the specific instruments or measures used in the study follows this, including a report of their psychometric properties, the alpha coefficient for the study sample, what each scale measures, its aims and why it was selected for this study.

Three ***outcome measures*** were used:

(i) **General Health Questionnaire**. The General Health Questionnaire (GHQ-28; Goldberg, 1978) is a 28-item checklist which assesses the level of psychosomatic symptoms (see Appendix 10, Section A) in terms of both a full scale score (maximum possible score = 84) and scores on four subscales, reflecting somatic symptoms, anxiety and insomnia, social dysfunction and severe depression (maximum possible score for each subscale = 21). Each item consists of a question asking whether the respondent has recently experienced a particular symptom or item of behaviour on a scale ranging from "less than usual" to "much more than usual" on a rating from "0" to "3". Thus, the higher the scores, the greater the level of symptoms or behaviour across the four domains of functioning and thus the aggregate scale total on the GHQ.

This measure has been reported to have good psychometric properties (Goldberg, 1978; Goldberg & Williams, 1988). Evidence of the four factor structure of the GHQ has been well established. It has also been shown to have good test-retest reliability and to correlate moderately well with other measures of stress. The GHQ was used in the study to measure the aggregate level of psychosomatic distress in parental primary caregivers as well as across the four subdomains of somatic symptoms, anxiety and insomnia, social dysfunction and severe depression.

(ii) Perceived Satisfaction with Life. A global rating of parents' perceived satisfaction with their current life situation (PSL; see Appendix 10, Section I), after taking everything into consideration, ie. their son/daughter with the learning disability, their adult life, etc., was used. This global rating measure was designed specifically for the present study. The item is scored on a 5-point scale, which ranges from 1 to 5. A score of 1 indicates "things are very good", a score of 2 indicates "things are fairly good", a score of 3 indicates "things are OK - not bad and not good", a score of 4 indicates "things are fairly bad" and a score of 5 indicates "things are very bad". The higher the score, the lower the caregiver's perceived satisfaction with life. The PSL rating was included to give a broad perspective of caregivers' own perceptions of their current life situation.

(iii) Services for People with Disabilities and their Caregivers. This measure was also used as a descriptor variable and is, therefore, explained in more detail later in this chapter (see also items A1, B2, C2 and D1 in Appendix 12, Part IV for further details). It comprises of 4 individual ratings on a 4-point scale, developed to measure the level of general satisfaction with services, effectiveness of care services and professionals separately, and the level of unmet need.

A variety of ***descriptor variables*** were selected to reflect a broad spectrum of characteristics which the literature and previous research suggests may be associated with family functioning, particularly levels of stress in carers of people with learning disabilities. The chosen variables are detailed below:

(i) Variables related to the Adult with the Learning Disability were gender; chronological age; position in family; medical problems; medication; other disabilities (physical, sensory); syndromes (eg. Down's, Rett's, Autism); global severity of learning disability as well as level of functioning across the subdomains of physical and developmental skills based on the Disability Assessment Schedule (Wing, 1989); nature and severity of challenging behaviours - typology and total scores on the Aberrant Behaviour Checklist (Aman *et al*, 1985a; 1985b; Clarke, Boer, Chung, Sturmey & Webb, 1996); and the motivating triggers to the most difficult challenging behaviour exhibited by the adult with the learning disability, as subjectively specified by the parental primary caregiver, using the Motivation Assessment Scale (Durand & Crimmins, 1988; Durand & Kishi, 1987).

Disability Assessment Schedule; DAS; Wing, 1989

The Disability Assessment Schedule (Holmes, Shah & Wing, 1982; Wing, 1989) is completed by conducting a structured interview (see Appendix 12, Part II) with an informant who knows the person with the disability well, in this study parental primary caregivers. The schedule consists of two broad domains: physical and developmental skills as well as behavioural abnormalities. Only the items relating to the physical and developmental skills were used in the present study. These fell under the following areas or subdomains: quality of social interaction; self-help; continence;

communication; domestic skills; literacy; mobility; vision and hearing. These areas or subdomains were comprised of at least one item, with the physical and developmental skills domain actually forming a total of 17 items (maximum possible score = 58). The precoded schedule is shown in Appendix 12, Part II, with each item having a series of ratings. The higher the score, in terms of the total domain as well as across the subdomains, the higher the level of functioning of the person with the disability. The reliability and validity of the DAS has been demonstrated by the developers of the instrument (Holmes *et al*, 1982; Wing, 1989). The DAS was chosen for this study to give an aggregate rating on the severity of learning disability as well as detailed profiles of functioning across all the different subdomains comprising the main domain of physical and developmental skills.

Aberrant Behaviour Checklist; ABC; Aman *et al*, 1985a; 1985b

The Aberrant Behaviour Checklist (see Appendix 10, Section H) is a 58-item rating scale which requires a rating of specified maladaptive behaviours from 0 (not at all a problem) to 3 (the problem is severe in degree), making a 4-point scale. The ABC yields both a full scale score (maximum possible score = 174) as well as five factors or subscales: (I) Irritability, agitation, crying (maximum possible factor score = 45); (II) lethargy, social withdrawal (maximum possible factor score = 48); (III) stereotypic behaviour (maximum possible factor score: 21); (IV) hyperactivity, non-compliance (maximum possible factor score = 48); and (V) inappropriate speech (maximum possible score = 12). Both the factor and item scores can be incorporated into the analysis (Clarke *et al*, 1996). The ABC has demonstrated reliability and validity in assessing maladaptive behaviour among people with cognitive impairment (Aman, Richmond, Stewart, Coyne & Lazarus, 1987; Newton & Sturmey, 1987). Findings (eg. Aman *et al*, 1985a; 1985b) show good internal consistency and test-retest reliability. Interrater reliability tended to vary across raters and subscales and ranged from mediocre to good, but was generally in the moderate range and acceptable for research purposes. In general, validity was established for most ABCL subscales. The scale has been widely used in a number of research studies in the area of learning of learning disabilities. The ABC was used in the present study to measure both the global severity and profiles of the challenging behaviours exhibited by the adult with the learning disability, as rated by the parental primary caregiver.

Motivation Assessment Scale; MAS; Durand & Crimmins, 1992

The Motivation Assessment Schedule (see Appendix 12, Part III) consists of 16 items, comprising 4 subscales, for sensory, tangible, attention and escape, and each item is rated on an ordinal scale of 0 to 6, 0 = Never; 1 = Almost Never; 2 = Seldom; 3 = Half the Time; 4 = Usually; 5 = Almost Always; 6 = Always. The maximum possible score for each subscale is 24, with higher scores being indicative of higher levels of motivation or triggers across each of the functions described in each of the four subscales. Respondents are asked to rate the frequency of the identified challenging behaviour occurring under particular setting conditions, as described under each item. An example of such a setting condition is "Does this person seem to do the behaviour to get you to spend some time with him or her?" as part of the attention subscale. All the items are then scored and added to give an indication of the motivators/triggers to the challenging behaviour as attributed or rated by the respondent. The scale has been shown to have acceptable validity but poor reliability (Sigafoos, Kerr & Roberts, 1994; Zarcone, 1991). The measure was included to determine the parental primary caregivers' attributions of the challenging behaviour exhibited by their son/daughter that they had subjectively identified as being the most challenging or difficult to deal with. The aim was to use the results of the MAS to see whether attributions or motivators to challenging behaviour acted as moderators or mediators to psychological stress and life satisfaction, rather than devise actual management programmes for the challenging behaviour, which meant that the scale having proven to have poor reliability was not a serious drawback in the selection of this particular measure.

(ii) Demographic variables were socio-economic status (SES); ethnic status; nature of employment; parental educational level; type of housing; car ownership; marital status; parental status (natural, foster, adoptive or step-parent); age of parents; total number of dependants at home and also the total number of children in nuclear family.

(iii) Parental and family resources. A number of published scales were used to assess the personal resources of the parents and the resources within the family system. These were all contained within the self-report questionnaires completed by parental primary caregivers. Parental personality was assessed using the Eysenck Personality Inventory (Eysenck & Eysenck, 1964) and locus of control was measured on the Brief Locus of Control Scale (Lumpkin, 1983). The parents' satisfaction with the marital relationship was assessed using the Measure of Marital Satisfaction (Kelso, Stewart, Bullers & Eginton, 1984) and social support was assessed using the Family Support Scale (Dunst, Jenkins & Trivette, 1984).

Eysenck Personality Inventory; EPI; Eysenck & Eysenck, 1964

The Eysenck Personality Inventory (EPI; Eysenck & Eysenck, 1964) is a 57- item scale in a YES-NO format that measures two major dimensions of personality, extroversion and neuroticism, but also includes a Lie Scale which identifies individuals showing a "desirability response set" (see Appendix 10, Section F). The Lie Scale is made up of 9-items, with a maximum possible score of 9. The Extroversion and Neuroticism Scales each comprised 24-items, with a maximum possible subscale score of 24. Item responses reflecting the subscale are scored 1, otherwise treated as 0, so high subscale scores reflect a high desirability response set, extroversion and neuroticism. It has been proven that the EPI has good psychometric properties (Eysenck & Eysenck, 1964). Direct evidence is available of the validity of the EPI as a descriptive instrument of the behaviour manifestations of personality. The EPI was used to measure the degree of extroversion and neuroticism in caregivers'.

Brief Locus of Control Scale; BLCS; Lumpkin, 1983

The Brief Locus of Control Scale (BLCS; Lumpkin, 1983) consists of 6 items, comprising two subscales, internal and external locus of control, made up of 3 items each, each with a maximum score of 15. Each item is rated on a 5-point Likert format, ranging from "1" to "5" representing "Strongly disagree" to "Strongly agree" (see Appendix 10, Section B). Higher scores represent higher external or internal locus of control. The Brief Locus of Control Scale was developed out of Rotter's (1966) original and longer version of the Locus of Control Scale. Adequate psychometric properties have been established for the shorter version of the scale (Lumpkin, 1983). It is also ideal to administer in any situation where space or time is limited.

Measure of Marital Satisfaction; MMS; Kelso *et al*, 1984

The Measure of Marital Satisfaction (Kelso *et al*, 1984) is an instrument designed to screen parents for marital problems. It consists of 13 individual items or groups of items which cover the common concerns of daily living in a family. The first part of the questionnaire deals with agreement between partners on particular matters; the next with compatibility, companionship, intimacy and conflict; and the final two questions with satisfaction. Most of the items are scored on a three point scale with the lowest score given for greatest satisfaction. For example, the answer to question number six, "How satisfied are you with your ability as a couple to talk over and resolve your differences?" is scored one if the parent is very satisfied, two if moderately satisfied and three if dissatisfied. Details of the scoring can be found in Kelso *et al*, 1984 and the full schedule is given in Appendix 10, Section E. Total scores range from 26 to 72, with higher scores reflecting greater marital dissatisfaction. The instrument has been demonstrated to have good reliability and validity (Kelso *et al*, 1984) and has been used in studies of families containing a member with a learning disability (eg. Sloper *et al*, 1991; Sloper & Turner, 1994). The instrument also includes questions about the effects of children on marital relationships. This measure was included in the study to assess the level of marital satisfaction as perceived by the parental primary caregiver.

Family Support Scale; FSS; Dunst *et al*, 1984

The Family Support Scale (FSS; Dunst *et al*, 1984) is an 18 item self report measure designed to assess the degree to which different sources of support are helpful to families rearing a young child. Each item is rated on a 5 point scale ranging from Not at All Helpful (0) to Extremely Helpful (4) (see Appendix 10, Section G). Different measures of support can be derived from the scale. The sum of the ratings for all 18 items provides an overall index of the degree of helpfulness of support. The items can also be grouped according to subcategories of support, and indices of helpfulness and number of sources of support available computed for each. Five sources (formal kinship, informal kinship social groups, professionals and professional groups) and two types (informal and formal) of support can be scored from the scale.

The FSS has been used in a number of studies examining the extent to which social support affects parental health and well-being, family integrity, parental perceptions of child functioning, and styles of parent-child interaction (see Dunst, 1985 for a review of these studies). The reliability and validity of the scale are acceptable (Dunst *et al*, 1984). The instrument is quick and easy to administer as well as comprehensive with regard to the range of sources of support rated. The FSS was used in this study to assess the number of sources and helpfulness of social support available to families.

(iv) Coping strategies. The COPE (Carver *et al*, 1989) is a multidimensional coping inventory to assess the different ways in which people respond to stress. The measuring instrument consists of 60 items, comprising 15 subscales of 4 items each, with a maximum subscale score of 12, on a 4-point rating scale ranging from “0” to “3” representing “Don’t use at all” to “Use a lot” (see Appendix 10, Section D). Higher subscale scores reflect more use of that particular coping style. Five scales measure conceptually distinct aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support); five scales measure aspects of what might be viewed as emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales measure coping responses that arguably are less useful (focus on and venting of emotions, behavioural disengagement, mental disengagement). Two additional subscales are given (humour, alcohol/drug use), each consisting of 4 items, which have been treated as the more exploratory aspects of the COPE.

Further, a second order factor analysis of the original 13 subscales have yielded four factors, each capturing three subscales. Factor one was composed of active coping, planning, and suppression of competing activities. The second factor was composed of seeking social support (both scales) and focus on emotion. A third factor was composed of denial and both mental and behavioural disengagement. The fourth factor incorporated acceptance, restraint coping, and positive reinterpretation and growth. Turning to religion failed to load on any of these factors, and is treated separately when the second-order factors are used in the analysis. Carver *et al* (1989) have demonstrated that the COPE has acceptable reliability and validity.

The COPE was used in this study to measure the ways in which parental primary caregivers coped with the problems related to their son/daughters' challenging behaviour. The individual subscales of the COPE are used in the descriptive part of the analysis, but the statistical analysis employs the four second order subscales, the turning to religion subscale and the two exploratory subscales, humour and alcohol/drugs.

(v) Social desirability. The short version of the Marlowe-Crowne Social Desirability Scale (MCSDS; Strahan & Gerbasi, 1972) was used to measure social desirability. The scale consists of 10-items, with a maximum score of 10, with a True-False format that measures social desirability (see Appendix 10, Section C). Item responses reflecting a socially desirable response are rated as 1, otherwise treated as 0. Thus, higher scores reflect greater social desirability. This shortened version has been favourably compared to the original Marlowe-Crowne Social Desirability Scale (Crowne & Marlowe, 1960) in terms of psychometric properties. Correlations have been found in the .80s and .90s. The psychometric adequacy of the shortened version of the scale is, in part, supported by cross-validation. The still shorter and reasonably parallel M-C 1 [10] (Strahan & Gerbasi, 1972) has been shown to be of use when administration time is highly limited and the attendant drop in reliability tolerable. Thus, the M-C 1 [10] was used in the study as a measure of the influence of social desirability on test responses.

The effects of social desirability on responses on self report measures has long been debated (eg. Block, 1965; Nevid, 1983; Strosahl, Linehan & Chiles, 1984), particularly in relation to the significant correlations often found between social desirability scores and other self report measures. The debate centres on whether such correlations are theoretically inconsistent with constructs being measured, and thus bring into question the validity of the measures, or whether the covariation is theoretically predictable, and thus may strengthen the case for the construct validity of the measures. If the latter case is argued, the measures must still be discriminable from each other and not be confounded.

In order to allow investigation of these issues in the present study the Marlowe-Crowne Social Desirability Scale was included in the questionnaires and the univariate relationships between outcome measures, which involved parents' reports, and their Marlowe-Crowne Social Desirability scores was examined. The only significant association found was between the GHQ Somatic Symptoms Subscale scores and Marlowe-Crowne Social Desirability scores for parental primary carers. Thus, there was little evidence for a social desirability 'response set' operating on the self report measures in the questionnaire and thus affecting validity. Neither was there any indication that measures of outcome and measures of social desirability were confounded.

(vi) Services for People with Learning Disabilities and their Families/Carers. Part IV of Semi-Structured Interview Schedule (see Appendix 12, Part IV) explores various aspects of ongoing care services and professional input as well as unmet need and gaps in services, concentrating over the last 12-18 months of usage by service-users, through a mixture of rating scales and open-ended questions (Bridgen & Todd, 1990; Humphreys, Lowe & Blunden, 1985; James, 1984; MacLachlan *et al*, 1987; Mitchell, 1990). Section A asks respondents to rate, in an overall, general sense, their level of satisfaction with the services (care and professional) that they received, using the following rating scale: 1 = Quite dissatisfied, 2 = Indifferent or mildly dissatisfied, 3 = Mostly satisfied, and 4 = Very satisfied.

In Section B, Question B1 asked caregivers what types of local care services (eg. respite care, day centres, parents' group, leisure activities, etc.) they had used in relation to their son/daughter. Question B2 asked respondents to rate these care services in terms of whether and how effectively they thought they had helped them to deal with their problems in relation to their son/daughter, using the following rating scale: 1 = No, they seemed to make thing worse, 2 = No, they really didn't help, 3 = Yes, they helped somewhat, 4 = Yes, they helped a great deal. Question B3 asked what generally made contact with the named services useful or helpful and question B4 asked what generally made contact with these services useless or unhelpful. The questions in Section C ran parallel to those in Section B, except professionals (eg. GP, social worker, psychologists, , etc.) were substituted for local care services.

Section D covered areas of unmet need, beginning by asking respondents to what extent they felt that local services and professionals had met their needs, using the following rating scale: 1 = None of their needs have been met, 2 = Only a few of their needs have been met, 3 = Most of their needs have been met, and 4 = Almost all of my needs have been met. Question D2 asked caregivers what they considered to be their special needs as arising from their son/daughter's difficulties and D3 asked what improvements or additional services were needed to better meet their needs. Section F of the interview was essentially for participants' to express their concerns and views about anything they felt to be necessary or important but had not been sufficiently or adequately addressed as yet by the interviewer.

2.4 Procedure

The participants were identified and recruited from local learning disability services in and around the boroughs of London. Two main recruitment methods were used: (1) Register of People with Learning Disabilities, in services where this information was available; (2) Local services, namely, Clinical Psychology Services, Community Teams, Care Management Teams, Social Services, Day Care Services, MENCAP and London Autism. Prior to this, clinical psychologists in learning disabilities services were contacted by telephone first by the researcher, briefly explaining the aims and methods of the study and requesting agreement to participate. Interested clinicians were then sent a full study protocol to further elicit their support and participation in the study in their health service area, which lead to contact with lead clinicians or managers of other types of learning disabilities services including voluntary organisations, social services and day centres.

First, using the register of people with learning disabilities, the register organisers identified the total number of adults with learning disabilities and challenging behaviour who were over and including the age of 18 and still living in their family home with their parents/carers. Second, managers of local services were contacted by telephone and then sent an information letter (see Appendix 2) which, if they wished to participate, explained their role within the study. They were also sent a brief protocol (see Appendix 3) outlining the nature and purpose of the research study as well as a decision tree (see Appendix 5) to guide the nature and extent of their actual involvement. Participating managers were asked to identify the total number of individuals using their service who fulfilled the study criterion, that is, adults exhibiting challenging behaviour and living at home with their parental carers.

Managers or register organisers were then given participant information letters with accompanying self-addressed envelopes to send to the parents/carers of the adults they had identified, to which they added the names of both parents, where relevant, as it was not assumed that mothers would always be the primary carers. An additional covering letter (see Appendix 6), written by participating services or register organisers, was also attached to all original study information letters to potential participants (see Appendix 7). This covering letter from services not only acted as a mediating link between potential participants and the researcher, but also emphasised the independent and confidential nature of the research study in that it was not actually linked to the actual service that was requested to send information letters to parents/carers. As reminder letters were intended to be sent to those parents/carers who did not reply initially, the reply return slip (see Appendix 8) was number coded, and managers or register organisers were asked to make a written note of the number code for each family on the supplied form (see Appendix 4). However, at a later point in the study, it became increasingly difficult to implement the second stage of issuing reminders because it proved to conflict with good practice. In other words this proved impractical in many services, particularly in relation to the resources of time and commitment, and was thus abandoned after attempts to follow-up with one service. So, although reminder letters were initially intended to be sent to parents/caregivers if no reply had been received from them after one month, this part of the recruitment procedure was forcibly removed during the actual implementation of the study.

A total of 24 services for people with learning disabilities were invited to participate in the study. Ethical permission was not given by the Local Research Ethics Committees of the relevant health service areas for 3 of the services that had initially agreed to take part, 3 services did not respond to the study protocol and/or manager information letter, 1 service was abandoned due to administrative and organisational difficulties, 1 service could not make the commitment because of time restraints and 1 service did not respond to the request by the final deadline. Thus, a total of 15 services actually took part in the research. Ethical permission for the study was granted by The Joint UCL/UCLH Committees on the Ethics of Human Research, which covered all these 15 services, but some of these services had to obtain separate ethical approval in line with their own service policy requirements (see Appendix 1).

The study procedure involved the collection of data through administration of questionnaires and conducting of a semi-structured interview. Each parental primary caregiver was given self-administered questionnaires to complete and interviewed. All potential parents/carers of these identified adults were sent a participant information letter about the research, via a local service, inviting them to participate in the study. This briefly outlined the nature and aims of the research study and, further, to enable parents/carers to understand why they had been specifically selected as potential participants, the criteria necessary for families to be involved was also provided. Thus, the caregivers of the identified people with learning disabilities and challenging behaviour were contacted and the primary parental caregiver invited to participate in the study. When invited to participate in the research, carers were informed about approximately how much time it will take them to complete both the self-report questionnaires as well as take part in the semi-structured interview. Families were given time to think about whether they wished to participate in the study, and asked to reply on an initial consent slip (see Appendix 8) using the pre-paid self-addressed envelope provided.

If they agreed to take part, each participant was followed up by a telephone call in order to explain further the details of the study, answer any questions consenting participants may have had, and to arrange a mutually convenient time to meet with them in their home or somewhere else of their choosing. All appointments were arranged at times and locations convenient to the caregivers. For example, many of the caregivers were willing to participate in the research during the day time when their sons/daughters were attending day care services. However, some caregivers, particularly those who were working, were interviewed during the week day evening because this time of the day was more convenient to them. All participants were sent a letter (see Appendix 9) confirming the time and date of the appointment as well as an outline of the study procedure together with a booklet of self-report questionnaires (see Appendix 10) to complete prior to the actual appointment, if they were able to do so, which would then be personally collected by the interviewer. For those participants who were unable to complete questionnaire items independently, the researcher had reassured them that they would have the opportunity to complete these at the appointment. All interviews were conducted in the participants' own homes by the same interviewer using the semi-structured interview schedule (see Appendix 12).

At the actual appointment, before conducting the interview and administering any uncompleted questionnaires, the participant was briefly reminded of the purpose and nature of the study and the right to withdraw their participation from the study at any stage without it affecting their rights and medical care. The interviewer further reiterated the strictly confidential and anonymous nature of all information given by participants. The researcher also answered any questions participants may have had and then asked them to sign a written consent form (see Appendix 11).

There were two phases to the actual appointment. Firstly, the uncompleted questionnaires were administered, that were later scored and collated, clarifying any concerns or questions that participants may have had. Secondly, a semi-structured interview was undertaken with participants, with actual interviews lasting approximately 20-60 minutes, which were all tape recorded, with the participants' verbal agreement, for facilitation of later analyses of responses and presentation in the form of interview transcripts. Tape-recording of interviews also allowed the interviewer greater scope to concentrate on the dynamics of the interview (Newson & Newson, 1976). Following this, participants were briefly debriefed, which was an opportunity for them to discuss the experience of taking part in the study and any concerns or issues arising from this, and for the researcher to make any recommendations as to who may be the best source of help and support with particular difficulties that participants have been experiencing, often the GP or the Key Worker was suggested as the first point of contact, particularly for participants who seemed stressed and quite vulnerable to the daily demands of life. All participants were then thanked for their help and participation, and told, upon its completion, they would get a written report of the main findings of the study. The average length of the appointment time was 2½ hours, ranging from 1½ to 4 hours.

2.5 Reliability

General Health Questionnaire Alpha reliability (Cronbach, 1951) for the present sample was 0.934 for the total scale, 0.862 for somatic symptoms, 0.869 for anxiety and insomnia, 0.383 for social dysfunction and 0.920 for severe depression.

Aberrant Behaviour Checklist Alpha coefficients for the present study sample are 0.955 for the total ABC score, 0.931 for Factor 1 (Irritability), 0.858 for Factor 2 (Lethargy), 0.843 for Factor 3 (Stereotypy), 0.879 for Factor 4 (Hyperactivity) and 0.801 for Factor 5 (Inappropriate Speech).

Motivation Assessment Scale Alpha coefficients for the present sample are 0.539 for the sensory subscale, 0.790 for the tangible subscale, 0.688 for the attention subscale and 0.607 for the escape subscale.

Eysenck Personality Inventory Alpha reliability for the Lie Scale is 0.4789, Extroversion Scale is 0.681 and Neuroticisim Scale is 0.782.

Brief Locus of Control Scale Alpha reliability is 0.451 for the internal and 0.546 for the external locus of control subscale.

Measure of Marital Satisfaction Alpha reliability for the present sample is 0.904.

Family Social Support Alpha reliabilities for the total family social support scale [0.558]. Five sources (formal kinship [0.2314], informal kinship [0.434], social groups [0.356], professionals [0.318] and professional groups [0.562]) and two types (informal [0.391] and formal [0.608]) of support.

COPE Alpha reliabilities are: active coping [0.734], planning [0.814], suppression of competing activities [0.716], restraint coping [0.616], seeking of instrumental social support [0.840]), seeking of emotional social support [0.870], positive reinterpretation [0.794], acceptance [0.647], denial [0.621], turning to religion [0.960]), focus on and venting of emotions [0.811], behavioural disengagement [0.588], mental disengagement [0.478]), humour [0.907] and alcohol/drug use [0.959]). Factor one [0.910], second factor [0.889], third factor [0.697] and fourth factor [0.785].

2.6 Missing Data

Missing data in the study mainly consisted of occasional response omissions on individual questions or scales for otherwise satisfactory interviews and questionnaires.

Attempts were made to minimise this by the interviewer scanning completed questionnaires during the visit to the family and checking on any missing data.

Missing data cause major problems in relation to the cumulative effect of occasional omissions on calculation of indices and on multivariable analyses. In this respect, when one or more of the components of a composite measure, or one or more of the factors in a multivariable analysis are missing, then all the data are deemed to be missing for that subject. In indices and analyses involving many measures the overall effect of this could be to severely reduce the sample size.

In order to minimise the possible bias and the reduction in sample size from missing data due to response omissions, a number of guidelines were adhered to (Sloper, Cunningham, Knussen & Turner, 1988): (I) Questions with more than 10% of data missing due to occasional response omissions were considered to be unreliable and/or biased and would not be included in the analysis. The criteria gave a minimum sample of 54 parental primary caregivers on questionnaire data. No questions were excluded on this basis. (II) Subjects who failed to respond to more than 10% of items required for a composite measure or index would be excluded from the calculation of that measure. This occurred for between 4 and 6 subjects on individual indices. (III) For the remaining response omissions on items included in indices, missing data were assigned a mean score. Thus, the respondent's mean score was obtained for valid items, and this was multiplied by the total number of items in the scale to produce an estimate of the respondent's likely total score. This was deemed to be valid where only the total scores, not individual item scores, were used.

CHAPTER THREE

Results

3.1 Data Analysis Strategy

Following the establishment of a data base, questionnaires were coded and entered onto computer files for analysis using the Statistical Package for the Social Sciences (Norussis, 1983). Indices were created for composite measures. The taped interviews were transcribed. The results chapter is divided into three main sections: a descriptive data analysis, a statistical data analysis, and a qualitative data analysis section.

Descriptive data analysis

The descriptive data analysis section will provide a summary of the mean summed scores, standard deviations and possible range of scores for each of the variables. The independent variables are the demographic characteristics, challenging behaviour, severity of learning disability, attributions of challenging behaviour, locus of control, social desirability, personality, marital satisfaction, social support, coping strategies and the four service-related ratings (general satisfaction with services; effectiveness of services; effectiveness of professionals; extent need met), also used as dependent variables. The dependent variables are, in addition to the four service-related ratings, health scores and satisfaction with life.

Statistical data analysis

The statistical data analysis section examines the statistical associations between the predictor and outcome variables, beginning with a series of preliminary bivariate correlations, anovas and t-tests to identify possible predictor variables to subsequently enter into multiple regression equations. Following this, in order to examine the relative importance of the study's hypothesised mediating and moderating variables in predicting parental primary caregiver outcomes, the results of ten separate multiple regression analyses are presented for each of the outcome variables measured in the present study.

The first stage of each analysis was to explore the univariate relationships between descriptor and outcome variables. At this stage different variables were designated as descriptor or outcome variables, according to the specific analysis. Thus, the four service-related ratings were designated as descriptor variables in relation to caregivers' perceived satisfaction with life and general health scores but were also investigated as separate outcome variables in order to delineate family and adult with disability related factors related to the four aspects of services assessed in the present study. The selection of variables for specific analyses was informed by the research questions generated by the aims and objectives of the study as well as a review of the outcome-research literature.

The relationships between outcome and predictor variables were examined using t-tests for dichotomous descriptor variables and correlations for continuous variables. The linearity of all relationships were examined to determine whether variables could be entered in a multiple regression analysis. All variables significantly related to outcome at the univariate level proved suitable for entry into multiple regression analyses.

For each outcome or dependent variable, a subset of descriptor or predictor variables were identified for inclusion in multivariate regression analysis. Descriptors were included if they related to the outcome at the 5% level of significance, or if they just failed to reach 5% but there were theoretical grounds for inclusion.

The major merits of multiple regression analysis are: (i) It provides a précis of the associations between descriptor and outcome variables by eliminating these descriptor variables whose covariance with the outcome measure is shared by other variables with more powerful associations. (ii) The regression equation indicates the maximum level of explained variance that is possible with the available information, and therefore the extent to which unknown or unmeasured factors may be important as indicators of the outcome variable. (iii) The equation identifies conditions and circumstances likely to predict the outcome measured, although causality cannot be presumed from cross-sectional data. (iv) The data may suggest possible causal models with at least some of the variables in the final equation. This can inform models for further longitudinal research.

The results can be seen to indicate which factors are most likely to be associated with good or bad outcome, and, in their association with poor outcome, to be indicators of vulnerability or risk. The combination of variables associated with outcome may be viewed as factors which are additive in the degree of risk for the family.

Qualitative data analysis

The third section presents the qualitative data analysis from the transcribed interview transcripts. The transcript material was used to form coding categories and the collated information is presented in tabular form for the following themes: contact with services, helpfulness of services, unhelpfulness of services, contact with services, helpfulness of professionals, special needs and improvements or additional services required by parental primary caregivers in relation to caring for their sons/daughters with learning disabilities and challenging behaviour.

3.2 Descriptive Data Analysis

In order to assess the nature and level of stress in parental primary caregivers, the means and standard deviations were computed for each of the stress-related health outcomes of psychological health, anxiety and insomnia, severe depression and social dysfunction. Table 3.1 shows the means and standard deviations of stress-related health outcomes obtained in parental primary caregivers.

Table 3.1 Means and standard deviations of stress-related health outcomes in parental primary caregivers

Measure	Mean Summed Score	SD	Range of Scores
GHQ			
Psychological Health	21.72	11.18	4-54
GHQ Subscales			
Social dysfunction	8.00	4.01	1-31
Anxiety and insomnia	6.10	3.74	0-15
Somatic symptoms	6.04	4.00	0-15
Severe depression	2.43	3.88	0-18

Using 0/1 coding and a score of 4/5 as the cut-off point for 'caseness', it was found that 97% of the study sample were in the clinical range of the GHQ. This is clearly an extremely high percentage of the study sample falling into the clinical range of psychological distress when perceived in absolute terms but also when compared with other populations. For example, the specificity value for caseness was 74% in a sample of patients attending a GP surgery (Medina-Mora, Padilla, Campillo-Serrano, Mas, Ezban, Caraveo & Corona, 1983) and 93% in a sample of patients with multiple sclerosis (Rabins & Brooks, 1981).

The nature and level of learning disabilities and challenging behaviour in the sons/daughters of parental primary caregivers were examined by computing the means and standard deviations for all the disability-related predictor variables. Table 3.2 gives the means and standard deviations for the aggregate severity level and nature of challenging behaviours and learning disabilities in the adults with a learning disability.

Table 3.2 Means and standard deviations of disability-related variables in adults with learning disabilities and challenging behaviour

Measure	Mean summed score	SD	Range of scores
Aggregate Challenging Behaviour	43.38	29.61	2-130
Aberrant Behaviour Subscales			
Irritability	13.47	11.32	0-39
Hyperactivity	12.48	8.72	0-32
Lethargy score	9.47	7.87	0-32
Stereotype score	4.67	4.85	0-18
Inappropriate speech	3.89	3.36	0-11
Severity of Learning Disability	41.50	11.24	9-58
Disability-Related Subscales			
Continence	13.98	3.61	0-16
Communication skills	5.96	1.76	2-8
Literacy skills	5.44	4.74	0-13
Self-help skills	4.54	1.60	1-6
Quality of social interaction	3.72	1.88	0-6
Mobility	2.57	.96	0-3
Vision	1.93	.26	1-2
Hearing	1.91	.35	0-2
Domestic skills	1.44	.69	0-2

Descriptions of the amounts and types of personal and socio-ecological coping resources available to parental primary caregivers were then obtained by computing the means and standard deviations for the predictor variables relating to personality, locus of control, family social support and marital satisfaction. The means and standard deviations for these measures are given in Tables 3.3 and 3.4.

Table 3.3 Means and standard deviations for the predictor variables of personality and locus of control in parental primary caregivers

Measures	Mean summed score	SD	Range of scores
Eysenck Personality Inventory			
Neuroticism (24 items)	13.28	4.64	1-20
Extroversion (24 items)	12.85	3.80	5-19
Lie Scale (9 items)	4.87	15.53	0-114
Locus of Control			
Internal locus of control	9.81	2.43	3-15
External locus of control	9.26	2.79	3-15

Table 3.4 Means and standard deviations for the predictor variables of family social support and marital satisfaction in parental primary caregivers

Measure	Mean Summed Score	SD	Range of scores
Family Social Support			
Aggregate score	17.36	6.75	4-33
Family Social Support			
Informal support	9.78	4.63	3-21
Formal support	7.98	3.95	1-16
Family Social Support			
Formal kinship	5.43	2.73	0-11
Professional groups	4.74	2.92	0-12
Professional	3.26	1.77	0-8
Informal kinship	2.50	2.26	0-9
Social group	1.63	2.10	0-8
Marital Satisfaction	40.77	9.53	24-63

Finally, means and standard deviations of the range of coping strategies utilised by parental primary caregivers were obtained. Summaries of the means and standard deviations of the individual COPE sub-scales are given, as well as their classification into second order subscales, in Table 3.5.

Table 3.5 Means and standard deviations of individual COPE sub-scale measures used by parental primary caregivers

COPE sub-scale	Second order coping category	Mean summed score	SD	Range of scores
Acceptance	Stoicism	7.88	3.00	0-12
Planning	Active planning and coping	7.43	3.04	0-12
Active coping	Active planning and coping	7.32	2.99	0-12
Positive reinterpretation and growth	Stoicism	6.79	3.12	1-12
Seeking of social support for instrumental reasons	Seeking social support	6.20	3.51	0-12
Seeking of social support for emotional reasons	Seeking social support	5.83	3.45	0-12
Restraint coping	Stoicism	5.81	2.62	1-12
Suppression of competing activities	Active planning and coping	5.71	3.06	0-12
Focus on and venting of emotions	Seeking social support	5.30	3.33	0-12
Mental disengagement	Active avoidance and denial	4.54	2.39	0-10
Humour	(Exploratory subscale)	4.52	3.61	0-12
Turning to religion		4.37	4.44	0-12
Behavioural disengagement	Active avoidance and denial	3.77	2.67	0-12
Denial	Active avoidance and denial	1.92	2.33	0-10
Alcohol and drug use	(Exploratory subscale)	0.85	1.94	0-8

3.3 Statistical Data Analysis

In order to examine the influence of possible stressors, coping resources and coping strategies on health and well-being, perceived satisfaction of life and service-related efficacy in parental primary caregivers, a series of ten separate multiple regression analysis were performed for each of the following outcome variables: aggregate health score, anxiety and insomnia, severe depression, somatic symptoms, social dysfunction, perceived satisfaction with life, general satisfaction with life, effectiveness of care services, effectiveness of professionals and extent caregivers' needs met by services.

Due to the small sample size and large number of predictor variables, it was further necessary to perform univariate analyses on all independent variables to assess their suitability for entry into the multiple regression analysis. Only those variables reaching 5% significance were retained for entry into multiple regression analysis.

Univariate Statistical Analyses

A series of t-tests and bivariate correlations were performed on each predictor variable in relation to each outcome measure. Tables 3.6 shows the continuous independent variables and Table 3.7 shows the dichotomous independent variables that were significantly associated with stress-related outcomes on aggregate health, anxiety and insomnia, severe depression, somatic symptoms and social dysfunction in parental primary caregivers.

Table 3.6 Predictor variables significantly associated with stress-related health outcomes in parental primary caregivers using bivariate correlations

	Stress-related health outcomes in parental primary caregivers				
Predictor Variable	*Health Score*	*Anxiety & Insomnia*	*Severe Depression*	*Somatic Symptoms*	*Social Dysfunction*
Severity of challenging behaviour	r = 0.391*	r = 0.436**	r = 0.373*		
Hyperactivity	r = 0.404**	r = 0.435**	r = - 0.278'		
Lethargy	r = 0.392**	r = 0.412**	r = 0.398**		
Stereotypy	r = 0.332*	r = 0.421**		r = 0.268'	
Irritability		r = 0.285'	r = 0.278'		
No of dependants at home	r = - 0.286*	r = - 0.318*			
No of children at home		r = - 0.317*		r = - 0.260'	
Neuroticism	r = 0.527***	r = 0.574***	r = 0.345*	r = 0.404**	
Internal locus		r = - 0.346*			
Behaviour attributed to sensory				r = 0.311*	
Behaviour attributed to attention		r = 0.278'			
Social desirability response				r = - 0.322*	r = - 0.282*
Marital satisfaction	r = 0.348*		r = 0.364*		
Support from social groups					r = 0.273*
Informal kinship		r = - 0.351*			
General satisfaction with services		r = - 0.291*			
Effectiveness of care services					r = - 0.275*
Extent needs have been met	r = - 0.291'				
Active planning and coping		r = 0.480**			
Seeking social support	r = 0.378**	r = 0.585***			
Active avoidance and denial	r = 0.486**	r = 0.487**	r = 0.545***		r = 0.435**
Stoicism		r = 0.278'			
Turning to religion	r = 0.300*				
Alcohol/drugs			r = 0.333*		r = 0.279*

' = trend towards significance * = p<0.05 **=p<0.01 ***=p<0.001

Table 3.7 Significant mean differences found between dichotomous predictor variables and stress-related health outcomes in parental primary caregivers using t-tests

Stress-Related Health Outcome Variables	Predictor Variable	Mean Scores (SD)		t-values (df)
Health Score	Natural parent	**Yes**	**No**	
		23.26	14.25	2.16*
		(10.99)	(9.33)	(45)
	Adult on medication	**Yes**	**No**	
		25.00	18.00	2.31*
		(12.86)	(7.57)	(40)
Anxiety & Insomnia	Gender of parental primary carer	**Female**	**Male**	
		6.92	3.36	2.99**
		(3.55)	(3.11)	(46)
Severe Depression	Physical disabilities	**Yes**	**No**	
		0.73	2.88	2.90*
		(1.20)	(4.22)	(51)
	Adult on medication	**Yes**	**No**	
		3.34	1.33	2.05*
		(4.71)	(2.18)	(41)

* = p<0.05 ** = p<0.01

It is clear from Tables 3.2 and Tables 3.3 that the severity and nature of challenging behaviour in the sons/daughters of parental primary caregivers are strongly associated with their general psychological health, anxiety and insomnia, and severe depression. Neuroticism scores were also strongly related to most aspects of stress-related health scores. Different styles of coping strategies were strongly associated with various aspects of health, particularly in relation to anxiety and insomnia in parental primary caregivers.

Next, a series of t-tests and bivariate correlations were performed on each predictor variable in relation to the outcome measure of perceived satisfaction with life. Table 3.9 shows the continuous independent variables and Table 3.2 shows the dichotomous independent variables that were significantly associated with the outcome variable of perceived satisfaction with life in parental primary caregivers.

Table 3.8 Predictor variables significantly associated with perceived satisfaction with life in parental primary caregivers using bivariate correlations

Predictor Variable	Perceived satisfaction with life
Severity of challenging behaviour	r = 0.343*
Hyperactivity	r = 0.317*
Irritability	r = 0.397**
Behaviour attributed to attempts to escape	r = 0.302*
Extent to which needs have been met	r = - 0.278*
Active avoidance and denial	r = 0.360*
Stoicism	r = 0.264'

' = trend towards significance * = p<0.05 ** = p<0.01

Table 3.9 Significant mean differences found between dichotomous predictor variables and perceived satisfaction with life in parental primary caregivers using t-tests

Perceived Satisfaction with Life Outcome Variable	Predictor Variable	Mean Scores (SD)		t-values (df)
Perceived satisfaction with life	Son/daughter attends day service	Yes 2.68 (0.84)	No 3.00 (0.00)	2.68** (49)
	Biological/natural parent	Yes 2.81 (0.80)	No 2.22 (0.83)	1.96' (51)
	Own Home	Yes 2.59 (0.79)	No 3.22 (0.83)	2.17* (51)

' = trend towards significance * = p<0.05 **=p<0.01

Tables 3.8 and 3.9 highlight the strong association between severity and nature of challenging behaviour in the adults with learning disabilities and the parental primary caregivers' perceived satisfaction with life, with more severe challenging behaviours, hyperactivity and irritability being associated with decreased levels of perceived satisfaction with life. The use of 'active avoidance and denial' as a coping strategy to deal with their sons/daughters' challenging behaviour was also strongly associated with lower levels of perceived satisfaction with life in parental primary caregivers.

Univariate analyses were then performed on each predictor variable in relation to the service-related outcome measures in parental primary caregivers. Tables 3.10 shows the continuous independent variables and Table 3.11 shows the dichotomous variables that were significantly associated with service-related outcomes on satisfaction with services, effectiveness of care services and of professionals, and extent to which needs were met.

Table 3.10 Predictor variables associated with service-related outcomes in parental primary caregivers using bivariate correlations

	Service-related health outcomes in parental primary caregivers			
Predictor Variable	*Service Satisfaction*	*Effectiveness of Care Services*	*Effectiveness of Professionals*	*Extent needs been met*
Severity of challenging behaviour	r = - 0.300*			
Stereotypy	r = - 0.292*			
Inappropriate speech	r = - 0.374**			
Mobility		r = - 0.278*		r = 0.325*
Hearing				r = 0.281*
Age of parental primary caregiver	r = 0.272'			
Professional groups support	r = 0.430**	r = 0.337*		r = 0.394**
Informal kinship		r = 0.310*		
Aggregate social support		r = 0.366*		
Alcohol		r = - 0.355**		
Humour				r = 0.364**

' = trend towards significance * = $p<0.05$ **= $p<0.01$

Table 3.11 Significant mean differences found between dichotomous predictor variables and service-related outcomes in parental primary caregivers using t-tests

Service-related Outcome Variables	Predictor Variable	Mean Scores (SD)		t-values (df)
Effectiveness of Care Services	Physical disabilities	Yes 3.73 (0.47)	No 3.32 (0.82)	2.16* (29)
	Other Disabilities (sensory and physical combined)	Yes 3.75 (0.45)	No 3.25 (0.84)	2.79** (49)
	Sensory disabilities	Yes 3.83 (0.41)	No 3.35 (0.80)	2.38* (11)
Effectiveness of Professionals	Physical disabilities	Yes 3.64 (0.51)	No 3.22 (0.65)	1.96' (20)
Extent Needs Met	Son/daughter attends day service	Yes 2.78 (0.86)	No 1.67 (0.58)	2.19* (51)
	Severe incontinence	Yes 3.08 (0.52)	No 2.61 (0.95)	2.26* (34)
	Own home	Yes 2.84 (0.81)	No 2.11 (1.05)	2.35* (51)

' = trend towards significance * = $p<0.05$ ** = $p<0.01$

Tables 3.10 and 3.11 illustrate the strong relationship between severity of challenging behaviour and service satisfaction. It is clear that, the more severe the challenging behaviour in their sons/daughters, the less likely are parental primary caregivers to be satisfied with services. However, a variety of variables relating to sources of social support and also disability-related characteristics are strongly associated with efficacy of service-related outcomes in parental primary caregivers. There are clearly different predictor variables associated with service-related outcome to those observed for health-related outcomes and perceived satisfaction with life.

Multiple Regression Analyses

GHQ Aggregate Health Score

Each of the 13 predictor variables (see Table 3.6 & 3.7) were then regressed onto aggregate health scores in the multiple regression analysis. The results of the final stepwise multiple regression equation (see Table 3.12) show that the hyperactivity-related challenging behaviours in adults with learning disabilities was a significant predictor of psychological health in caregivers. The coping strategy of "seeking social support" and active avoidance and denial" were also found to be important predictors of psychological health.

Table 3.12 Stepwise multiple regression solution for parental primary caregivers' aggregate health score

Predictor Variable	Beta	P
Hyperactivity	.309667	.0479
Seeking social support	.362409	.0150
Active avoidance and denial	.394422	.0084

$R^2=0.62$ $p<0.001$

GHQ Anxiety and Insomnia

Each of the 17 predictor variables (see Table 3.6 & 3.7) were then regressed onto anxiety and insomnia scores in a multiple regression analysis. The results of the final stepwise multiple regression equation (see Table 3.13) show that "seeking social support" and "active avoidance and denial" as a means of coping with their sons/daughters' challenging behaviour as well as neuroticism scores were significant predictors of anxiety and insomnia in parental primary caregivers.

Table 3.13 Stepwise multiple regression solution for parental primary caregivers' anxiety and insomnia

Predictor Variable	Beta	P
Neuroticism	.262104	.0355
Seeking social support	.533001	.0001
Active avoidance and denial	.359642	.0039

$R^2=0.66$ $p<0.001$

GHQ Severe Depression

Each of the 10 predictor variables (see Table 3.6 & 3.7) were then regressed onto severe depression scores in the multiple regression analysis. The results of the final stepwise multiple regression equation (see Table 3.14) show that lethargic behaviours in their sons/daughters were the most significant predictors of severe depression in parental primary caregivers.

Table 3.14 Stepwise multiple regression solution for severe depression in parental primary caregivers

Predictor Variable	Beta	P
Lethargy	.521659	.0037

$R^2=0.27$ $p<0.005$

GHQ Somatic Symptoms

Each of the 5 predictor variables (see Table 3.6 and 3.7) were then regressed onto somatic symptoms in the multiple regression analysis. The results of the final stepwise multiple regression equation (see Table 3.15) show that neuroticism scores were the most significant predictors of somatic symptoms in parental primary caregivers.

Table 3.15 Stepwise multiple regression solution for somatic symptoms in parental primary caregivers

Predictor Variable	Beta	P
neuroticism	.424989	.0036

$R^2=0.18$ $p<0.005$

GHQ Social Dysfunction

Each of the 5 predictor variables (see Table 3.6 & 3.7) were then regressed onto social dysfunction symptoms in the multiple regression analysis. The results of the final stepwise multiple regression equation (see Table 3.16) show that the use of "active avoidance and denial" as a coping strategy to deal with the challenging behaviours of their sons/daughters was the most significant predictors of social dysfunction in parental primary caregivers.

Table 3.16 Stepwise multiple regression solution for social dysfunction in parental primary caregivers

Predictor Variable	Beta	P
Active avoidance and denial	.446381	.0021

$R^2=0.19$ 0.005

Perceived Satisfaction with Life

Each of the 10 predictor variables (see Table 3.8 & 3.9) were then regressed onto perceived satisfaction with life in the multiple regression analysis. The results of the stepwise multiple regression equation (see Table 3.17) show that the irritability of behaviours in their sons/daughters with the disability and the degree of marital satisfaction were the most significant predictors of perceived satisfaction with life in parental primary caregivers.

Table 3.17 Stepwise multiple regression solution for perceived satisfaction with life in parental primary caregivers

Predictor Variable	Beta	P
Irritability	.447647	.0047
Marital satisfaction	.433361	.0059

$R^2=0.51$ $p<0.001$

General Satisfaction with Services

Each of the 5 predictor variables (see Table 3.10 & 3.11) were then regressed onto general satisfaction with services score in the multiple regression analysis. The results of the stepwise multiple regression equation (see Table 3.18) show that the behaviours reflecting inappropriate speech in their sons/daughters with the disability were significant predictors of low general satisfaction with services. Support from professional groups was also a very significant predictor of service satisfaction for parental primary caregivers.

Table 3.18 Stepwise multiple regression solution for service satisfaction in parental primary caregivers

Predictor Variable	**Beta**	**P**
Inappropriate Speech	-.299370	.0395
Professional Groups	.360385	.0143

R^2=0.23 p<0.01

Effectiveness of Care Services

Each of the 7 predictor variables (see Table 3.10 & 3.11) were then regressed onto effectiveness of care services in the multiple regression analysis. The results of the stepwise multiple regression equation (see Table 3.19) show that the aggregate level of social support was a significant predictor of effectiveness of care services in parental primary caregivers.

Table 3.19 Stepwise multiple regression solution for service effectiveness in parental primary caregivers

Predictor Variable	**Beta**	**P**
Aggregate Social Support	.366388	.0144

R^2=0.13 p<0.05

Effectiveness of Professionals

The predicted variable (see Table 3.11) was regressed onto effectiveness of professionals in the multiple regression equation but it failed to enter the equation.

Extent Needs Met

Each of the 7 predictor variables (see Table 3.10 & 3.11) were then regressed onto extent needs met scores in the multiple regression analysis. The results of the stepwise multiple regression equation (see Table 3.20) show that the social support from professional groups and the use of humour as a coping strategy to deal with their sons/daughters' challenging behaviour were significant predictors of the extent to which needs were met for parental primary caregivers.

Table 3.20 Stepwise multiple regression solution for extent needs met in parental primary caregivers

Predictor Variable	Beta	P
Professional Groups	.352959	.0064
Humour	.325879	.0114

$R^2=0.25$ $p<0.001$

3.4 Exploratory Qualitative Data Analysis

The results of the statistical data analysis relating to service-related outcomes shows that the factors predicting efficacy of services are very different to those predicting stressor-related outcomes. In addition, the amount of variance accounted for in these analyses was small. Thus, it appears that the process model of stress and coping (Lazarus, 1966) cannot be suitably be applied to service-related outcomes, particularly because more information on possible factors determining service-related efficacy is needed. This highlights further the importance of simultaneously obtaining qualitative in-depth data directly from parents or primary caregivers of adults with learning disabilities and challenging behaviour, which the present study was able to do. The results of the exploratory qualitative data analysis that was undertaken are presented next. Table 3.21 shows the mean and standard deviations of the four service-related outcomes.

Table 3.21 Means and standard deviations for the service-related outcome variables

Measure	Mean Summed Score	SD	Range
Service Related Outcomes			
Effectiveness of services	3.40	.77	2-4
Effectiveness of professionals	3.31	.64	2-4
General satisfaction with services	2.92	.77	1-4
Extent needs met	2.72	.89	1-4

From the transcribed interview material, a preliminary content analysis was undertaken and broadly similar responses collapsed into coding categories to look for commonalties and shared experiences, but the individual variety and richness of caregivers' responses were retained to enable insight and knowledge to be gained about individual differences. Parental primary caregiver were initially asked about the types of care services that they had used in relation to their son/daughter with the learning disability. The most frequent responses are summarised in Table 3.22.

Table 3.22 Contact with care services

Contact with Care Services	No
Respite care	36
Leisure/social clubs for people with disabilities (Gateway club/MENCAP/Wednesday club)	32
Day Centre	31
Befriender/home respite scheme	12
College	10
Leisure/social clubs for mainstream/integrated activities	9
Training Centre - Workshop	9
Care attendant/carer	6
Work	5
School	3

Table 3.22 shows that the most frequently used services were respite care, befriender/home respite care scheme, day centres, college, workshop/training centres, school, leisure/social clubs for people with disabilities and also integrated activities, workshop/training centres and home care attendants. Less frequent responses included tea visits to respite care, part-time classes at an adult learning centre for people with disabilities, private "sitting" service, church membership, one-to-one workers, and specialist support organisations such as London Autism, and also privately set up parent support groups.

Next, parental primary caregivers were asked about the helpful or useful aspects of these care services, and their most frequent responses are summarised in Table 3.23.

Table 3.23 Helpful/useful aspects of care services

Helpful/Useful Aspects of Care Services	No
Chance to have a break from son/daughter	21
Break means can attend to own needs	21
Gives son/daughter a chance to have a break away from home	20
Chance to meet people and make friends	20
Break gives feeling of freedom	20
Break allows time and space to myself	19
Break gives flexibility to be flexible in my own life	19
Son/daughter loves/likes/enjoys going to centre/respite care/social clubs	19
Gives me time to myself	15
Widens experience of son/daughter	15
Break enables me to or gives opportunity to do activities I enjoy	14
Staff working closely or closer with me	13
Independence is encouraged	13
Encourage integration into community	13
Gets a stimulus with the different activities	12
Son/daughter enjoys activities	12
Improves self-esteem of son/daughter	10
Son/daughter more outgoing	10
Physical support helps cope	10
Helps carer and son/daughter adjust to possible future residential care	9
Help to fit into society as best as person with a learning disability can	8
Increases communication skills	8
Broadens horizon and improves social skills	8
Nice to know help and advice is constantly available	7
Staff at Adult Centre supportive and considerate	6
Took up expressed concerns and translated them into action	6
Gives person with a learning disability a very full life	6

Table 3.23 shows that the most useful or helpful aspects of services were primarily giving the parental primary caregivers a break away from the demands of caring for their sons/daughters, but also gives the person with the disability a chance to have a break away from the family home, being able to communicate concerns with staff and be taken seriously, and obtain helpful advice and support during times of need . The son/daughter was frequently reported to enjoy attending these care services, primarily because it gives them the chance to engage in social and life activities, socialise and meet new people, improve their social and life skills, broaden their horizon and become more integrated into community life. Some less frequent responses were that the service enabled parental caregivers to manage their sons/daughters' special needs, for example, special dietary requirements and behaviour management strategies.

Parents were next asked about the not so useful or unhelpful aspects of services, and their most frequent responses are summarised in Table 3.24.

Table 3.24 Unhelpful aspects of care services

Unhelpful Aspects of Care Services	No
Staff irresponsible and neglectful of needs	8
Staff/service difficulties with person with learning disability	8
Lack of staff	7
Day Centre does not help to improve skills and abilities	7
Strained/difficult communications between staff and carer	6
Little/lack of continuity with staff/high turnover	6
Centres too big with big groups	5
No support or financial help	5
Needs not taken seriously	5
Not occupied enough at day service	4

Table 3.24 shows that parental primary caregivers frequently found that the day centre did not help to improve their sons/daughters' skills and abilities and were often left unoccupied, staff experienced management difficulties with their sons/daughters,

strained/difficult communications between staff and them, and lack of staff and little staff continuity because of a high staff turnover, particularly staff being irresponsible and neglectful of need, and that centres were too big with big groups. Less frequent unhelpful responses elicited included cultural conflicts, particularly lack of attention to the needs of ethnic minority groups, and also lack of recognition of the specialist needs of adults with specialist diagnosis such as autism.

Next, parental primary caregivers were asked about their contact with professionals. The most frequent responses elicited from them are given in Table 3.25.

Table 3.25 Contact with professionals

Contact with Professionals	**No**
General Practitioner (GP)	43
Social Worker	34
Dentist	25
Psychiatrist	20
Community Nurse	12
Clinical Psychologist	11
Occupational Therapist	8
Key Worker	6
Optician	6
Speech Therapist	5
A & E - Nurses and Doctors	5

Table 3.25 clearly illustrates that GPs, social workers, dentists, psychiatrists, community nurses and clinical psychologists were the most frequently consulted professionals. Less frequent contact was made of professionals such as music therapists, art therapists, counsellors and link workers. Specialists services such as aromatherapy and acupuncture were reported to have been received, albeit privately.

Parental primary caregivers were then asked to report on the helpful or useful aspects of professional services received and their most frequent responses are given in Table 3.26.

Table 3.26 Helpful aspects of professional services

Helpful Aspects of Professional Services	No
Generally very good	28
Can talk very readily to him/her	27
Professional aware of special needs	24
Very understanding/being understood	23
Addressing medical/physical health care aspects of son/daughter	19
Emotional and moral support offered	17
Kindness	15
Very caring	15
Being taken seriously	14
Prescribing appropriate medication	12
Stress removed by being able to share the burden	12
Practical support offered	12
First class medical attention	11
Their willingness to help sort problem out	10
Specialist in dealing with the handicapped/disabled	9
Patient and sympathetic	9
Enhancing independence through personal development	7
Availability of professionals	6

Table 3.26 shows that the most common helpful experiences included professionals being very understanding of families and their circumstance, parents could talk to them readily, they were being taken seriously. They felt that the stress or burden of care could be shared with professionals, who were also described as patient and sympathetic, available, willing to sort out difficulties, even enhancing the independence and personal development of their sons/daughters. Caregivers felt that, generally, the professionals were aware of their special needs, addressed the medical/physical aspects of care relating to their sons/daughters, including the prescription of appropriate medication. Less frequent responses included professionals being able to explain financial packages and availability of services, provide physical aids for their sons/daughters and co-ordinate all aspects of services through a link worker scheme.

Next, the unhelpful aspects of services were elicited and the most frequent responses of parental primary caregivers is given in Table 3.27.

Table 3.27 Unhelpful aspects of professional services

Unhelpful Aspects of Professional Services	No
No constructive advice or help offered	18
Parents get frustrated with professionals	12
Urgent express need overlooked/minimised	10
Due care and attention not given to physical health needs	10
Services not specialised enough	9
Professionals inexperienced - don't have a clue	9
Difficult to get hold of a social worker diplomatically	7
Mismatch of need and meeting that need	6
Having to chase them up rather than them making themselves known	6
No satisfactory resolution/diagnosis	5
GP unwilling to acknowledge disability	5
Parents have to repeatedly give a history of problems upon meeting different professionals	5
Professionals working in isolation - lack of effective multidisciplinary communication/sharing knowledge	4
Professionals use long words/jargon	4
Waiting time for referral appointments very long	3

Table 3.27 shows that the most unhelpful aspects of professional services to parental primary caregivers included having to chase professionals rather than "be sought", no satisfactory resolution or diagnosis of problems obtained, many professionals worked in isolation, resulting in lack of effective multidisciplinary communication and sharing of knowledge, subsequently leading to parents having to repeatedly give a history of problems upon meeting different professionals. Caregivers felt professionals used long words or jargon, ignored, overlooked or minimised their urgently expressed needs, and due care and attention was not given to their physical and health needs. Less frequent responses relating to unhelpfulness of professionals included waiting times for referral to professionals was too long, not being helped to understand and manage the behaviour problems of their sons/daughters and out of hours help not available.

Next, parental primary caregivers were asked what they considered to be their special needs in relation to caring for a son/daughter with a disability. Their most frequent responses are given in Table 3.28.

Table 3.28 Special needs

Special Needs	No
Respite care when needed	29
Have a real break from caring	24
Needs need to be identified	13
Somebody to listen when things get bad	13
Some emotional support - knowing someone's available	13
Carer would like son/daughter to be more independent through developing life skills	11
Want appropriate residential care planned and delivered in present	11
Short time respite care so have evening alone	10
Residential care in future required	10
Help to deal with the behaviour	10
Wants more professional care during the day	8
Adequate leisure activities	8
Need key worker to actively develop life skills	5

The most frequently expressed special needs of parental primary caregivers and their families were to have respite care and "a real break from caring", their sons/daughters to become more independent through developing life skills, want appropriate residential care planned and delivered in the present, adequate leisure activities, emotional support, particularly in times of crises, and help with management strategies in relation to the challenging behaviour exhibited by their sons/daughters. Less frequent responses were wanting better transport, more funding and organisation of holidays for their sons/daughters, availability of counselling/psychotherapy, and also acupuncture, massage and hydrotherapy related facilities.

Parental primary caregivers were next asked about any improvements they felt needed to be made to existing services to better their needs. Their most frequent responses are given in Table 3.29.

Table 3.29 Further improvements needed

Further Improvements Needed	No
Individual needs should be attempted to be met	34
More money should be provided to specialist groups	15
Encourage parents to expect help and not left to get on with it alone	14
More contact with Social Services/Social Worker	12
More support required	12
More resources needed in the system to maintain motivation and enthusiasm	11
More information about service availability	11
Improve socialisation skills	11
More resources/time available	10
Relevant services should be provided in relation to identified need	9
It would be nice to have a befriender to come over in the evening to either sit in with or take out son/daughter	9
Increased contact with social worker for counselling and discussion of family issues/problems relating to son/daughter	8
Someone you feel understands the situation - not just academic but practical experience	8
Support groups should be set up for parents	8
Would be helpful to know somebody is readily available if you need any kind of help in an emergency/crisis - provision of a safety net - a secure base	7
Carer required on a day-to-day basis	7
More specialist training in specialist needs	7
People should be more understanding towards Special Needs	7
Accommodating and flexible in provision of short term emergency basis care: arrangement and availability of respite care	6
Better money resources needed to help support groups	6
Increased choice and availability of residential care	6
Smaller groups are needed	6
More social activities should be available at weekends	5

Table 3.29 shows that the most frequent improvements necessary were more the need for support groups to be set up for parents, improvement of socialisation skills in people with disabilities, more professional and service support to be made available to parents so as not to feel “alone and abandoned”, better resources put into the service, particularly specialist services for specific diagnostic groups such as autism. There was a significant number of caregivers who felt that services and professionals must attend to individual needs and not adopt a “one for all” approach. Less frequent

responses were improvements needed were increased facilities to befriend their sons/daughters into mainstream society and a "link worker to bring all aspects of the system together". Thus, although parental primary caregivers would like to see improvements being made to existing services, they so seem also to be quite positive about the services they do use and the professionals they have contact with, as reflected in the ratings shown in Table 3.21.

CHAPTER FOUR

Discussion

4.1 Preamble

This chapter will be broadly divided into four sections. It will begin by discussing the main findings of the study in relation to the questions and hypotheses generated in the introductory chapter of this thesis. It will then focus on the implications of the findings for parental primary caregivers in relation to their needs, views and experiences of learning disability services. This section will include a discussion of the unexpected findings of the study as well as its limitations to its generalisability and methodology. This is followed by a review of the implications for future research, highlighting particular aspects that need further attention and study. Implications for service organization and delivery will also be discussed as well as for clinicians and practitioners, in both mental health and learning disability services, engaged in clinical practice.

4.2 A summary of the main findings

The results of the study can be seen to indicate which factors were most likely to be associated with good or poor outcome in parental primary caregivers as measured by the GHQ health-related variables, perceived satisfaction with life and, in a more exploratory way, service-related efficacy. For the stress-related health outcomes (aggregate health score, anxiety and insomnia, severe depression, somatic symptoms, social dysfunction), in the univariate analyses, the variables relating to both severity and aspects of challenging behaviour, neuroticism and types of coping strategies used to deal with their sons/daughters' challenging behaviour were found to be significantly associated with psychological ill-health in parental primary caregivers.

Indeed, the GHQ specificity value of 97% for psychological 'caseness' clearly suggests a significantly high level of psychological distress in parental primary carers of adults with learning disabilities and challenging behaviour. Given that only 13% of the total 420 families that were identified as fulfilling the study criteria had participated in the study, this high level of 'caseness' seems to suggest that those parental primary caregivers who volunteered to take part in the study perhaps did so as a way of indirectly letting their need for help and support, both psychological and physical, be know to learning disability services and professionals providing services to people with learning disabilities, their caregivers and families.

The severity and nature of challenging behaviour in the sons/daughters of parental primary caregivers was clearly strongly associated with their general psychological health and well-being, anxiety and insomnia, and severe depression. This supports the findings of some of the studies reviewed earlier (eg. Carr, 1990, Quine & Pahl, 1985). Most behaviour-related variables (severity of challenging behaviour; hyperactivity; lethargy; stereotypy; irritability) were significantly associated with psychological ill-health, anxiety and insomnia, and also severe depression in parental primary caregivers, but somatic symptoms and social dysfunction were not related to challenging behaviour in adults with learning disabilities.

Neuroticism scores were also strongly related to psychological health and well-being, anxiety and insomnia, severe depression and somatic symptoms in parental primary caregivers, but not social dysfunction. This relationship also supports the findings of Sloper *et al* (1991) and Sloper & Turner (1994). Different coping strategies to cope with their sons/daughters' challenging behaviour were strongly associated with various aspects of health in parental primary caregivers. The use of 'seeking social support', 'active avoidance and denial' and the 'turning to religion' as ways of coping were significantly associated with poor psychological health in parental primary caregivers, as they were for anxiety and insomnia, in addition to 'active planning and coping', with the exception of 'turning to religion'.

These results provide a clearer empirical base for understanding the important role that stressors, coping resources and coping strategies may play in determining mental and physical well-being in parental primary carers of adults with learning disabilities and challenging behaviour. The results of the series of stepwise multiple regression equations for these five GHQ health-related outcomes highlighted some important differences and similarities in the variables that predicted different health-related outcome.

In relation to aggregate health scores, the multiple regression equation found that hyperactivity and both 'seeking social support' and 'active avoidance and denial' as ways of coping with challenging behavior were significant predictors of psychological ill-health in parental primary caregivers. These apparently mixed and contradictory findings relating to the use of coping strategies are somewhat unexpected findings because, although the use of 'active avoidance and denial' is a maladaptive coping style, the use of 'seeking social support' is considered in the literature to be an adaptive method of coping (eg. Carver *et al*, 1989). However, the literature has also shown that sources of social support can be stressful as they can be helpful (Beresford, 1994), and it may be that parental primary caregivers are not able to elicit appropriate or helpful sources of social support, either emotionally or practically.

Further, psychological disturbance can set up a vicious circle, whereby anxiety and depression in parental primary caregivers can lead to them seeking inappropriate social support, because of the lack of skills and abilities in eliciting appropriate support, which can lead to a further depletion of resources and, in turn, increased psychological disturbance. With the entry of behaviors relating to hyperactivity into the multiple regression equation, parental primary caregivers are likely to feel more anxious at their inability to appropriately manage the behaviours, which again can set up another vicious circle. However, the transactional nature of the model of stress and coping used in the study as well as its cross sectional methodology makes it impossible to make such causal inferences per se, but such hypotheses can form the basis for further research and clinical assessment.

Neuroticism scores were significant predictors of depression and also anxiety and insomnia in the multiple regression equation. Neuroticism has been found to be strongly associated with locus of control beliefs. It appears to be a personality trait in parental primary caregivers and this can clearly predict their levels of stress over and above those accounted for by challenging behaviour, but which is likely to feed into the ways in which coping strategies are utilized in managing challenging behaviour.

In relation to perceived satisfaction with life in parental primary caregivers, behaviour problems were also significant predictors of low satisfaction with life as well as marital satisfaction. This outcome variable seems to be linked to socio-economic resources, which may be depleted as the challenging behaviour of the adult with the learning disability is likely to have additional financial costs of long-term caring by parental caregivers. The exploratory qualitative data analysis has shed further light on these findings, where it is clear that parents have to make financial contributions to the services that their sons/daughters use, which can be become increasingly burdensome as their carers age. Similarly, caregivers' management of behaviour problems in their sons/daughters is likely to be emotionally draining as well as unavoidably physically taxing. All these factors are perhaps inevitably likely to influence the degree to which caregivers obtain or feel satisfaction with their lives.

Further, it seems that the degree of marital satisfaction is also related to perceived satisfaction with life because of the mutual benefits to be gained in having a supportive spouse/partner to help share the burden and task, physically, materially and emotionally. The nature of the marital relationship, in turn, is likely to also affect the way in which the financial and psychological costs of behaviour problems in the adult with the learning disability are managed or resolved by their caregivers, which will clearly affect the latter's degree of perceived satisfaction with life and living.

Disability-related variables and social support variables entered into the multiple regression equation for service-related outcomes in parental primary caregivers, suggesting that factors related to service-related efficacy are different to those for perceived satisfaction with life and health-related outcomes. The qualitative aspects of the study has supported this and highlights the different ways that services and professionals can be helpful or unhelpful and what parents need to reduce or minimize their levels of distress and ill-health in caring for their sons/daughters.

4.3 Implications for Service Organization and Delivery

It has been shown that parental primary caregivers have differing needs in relation to caring for their son/daughter with the disability and also managing their challenging behaviours. Services and professionals, across both learning disability and mental health specialties, need to pay particular attention to the ways in which they organize and deliver their 'goods' to this particular client group. They need to increase their focus on providing more activities for adults with learning disabilities and showing challenging behaviour. Services and professionals further need to concentrate on developing life skills and independence as well as improving socialisation skills in the sons/daughters of parental primary caregivers. Increased facilities to befriend adults with both a learning disability and exhibiting challenging behaviour and integrate them into mainstream society should be made available. Adequate resources should also be invested into specialist services for specific diagnostic groups such as autism and Aspergers' Syndrome.

It is further crucial for services and professionals to support the efforts of parental primary caregivers by responding to their expressed needs for more parental support groups to be set up. In addition, more professional and service support should be made available to parents so as they do not feel "alone and abandoned" in their role as primary caregivers. Services particularly need to be better organized and information needs to be made more available to families about things like service or professional availability and financial perks or benefits. They need to acknowledge the challenges and demands that these parental primary caregivers face, the limited informal sources of support they have at their disposal, as well as the wider impact on the family and social network. Services and professionals need to offer more support, both practical and emotional, to parental primary carers of adults with learning disabilities and who exhibit challenging behaviour. A link worker who could bring together all the different aspects of the various agencies and systems for caregivers and their families would be particularly welcomed by caregivers as a means of gaining easier access to relevant services and professionals. It is vital for services and professionals to attend to caregivers' needs on an individual basis and not adopt a "one for all" approach, thus providing the "personal touch" and enabling caregivers to get from services a sense of personal commitment and understanding of their unique predicament in caring for a son/daughter with a learning disability and shows challenging behaviour.

4.4 Implications for clinicians and clinical practice

Several implications for clinicians and clinical practice arise from the findings of the present research study. Challenging behaviours in adults with learning disabilities are significant predictors of psychological ill-health and distress in parental primary caregivers. One important way in which clinicians and practitioners can help parental primary caregivers is by devising behavioral management strategies to enable them to handle the behaviours exhibited by their sons/daughters. Indeed, this was a need that was clearly expressed in the more exploratory aspects of the study. This can be an important advance in terms of intervening behaviorally on the 'vicious circle' phenomena to reduce challenging behaviours and thereby the associated distress. This is likely to set up a 'virtuous circle' in which reduced behaviours in their sons/daughters are likely to lead to increase confidence and self-esteem in parental primary caregivers. This, in turn, may produce more positive attributions about the challenging behaviour, resulting in more skillful handling of them, and increasingly more confidence in parental primary caregivers' skills and abilities, which is most likely to lead to improved physical and mental health in caregivers' as well as increase the likelihood of obtaining greater satisfaction with their day-to-day life.

Another intervening point can be through the use of cognitive therapy (Beck, 1976) which can be used to identify and challenge maladaptive, negative or irrational beliefs and dysfunctional assumptions about themselves, others and the world. The importance of this approach is supported by the finding that neuroticism was a strong predictor of severe depression as well as anxiety and insomnia in parental primary caregivers. Depression and anxiety in parental primary caregivers have been found to relate to negative attributions and assumptions that are likely to lead to their withdrawal from social networks or inappropriately seeking social support, resulting in further depressive and anxious attributions. In addition to a consultative, supervisory and training role, clinical psychologists have a particularly significant role to play in identifying, assessing and treating parental primary caregivers who are distressed. It may be that their negative attributions are making it difficult for them to manage the challenging behaviours in their sons/daughters, leading to downward spirals of distress and ill-health. This implies that integrated cognitive-behavioral therapy may help to reduce these pathways that lead to distress.

Another important way that clinicians can empower parental primary caregivers in relation to caring for their sons/daughters' challenging behaviour is by using family-based models. The exploratory aspects of the study highlighted the impact that challenging behaviour has on all aspects of family life and caregivers' needs for professional help in enabling the whole family to manage or handle the challenging behaviours shown by the adult person with the learning disability. The need for family-based as well as individual counseling in relation to the impact of challenging behaviour on parental primary caregivers on the whole family has been clearly seen being expressed in the present study, but this area has not been well researched.

4.5 Implications for future research

A number of limitations to the present study provide the basis for future research practice in the area of the psychological impact of challenging behaviour in parental primary caregivers of adults with learning disabilities. The voluntary nature of the present sample makes the findings of the study difficult to generalize and, therefore, further studies need to be undertaken that consistently illustrate common trends and differences. Further, the cross-sectional design of the study, makes it extremely difficult to make adequate causal inferences about predictor and outcome variables, so further research using a longitudinal design is necessary to widen knowledge bases and consequently improve clinical skills, techniques and practice.

One major limitation of the study was in its lack of representation of parental primary caregivers from ethnic minority groups who were unable to read and speak English. It was previously recognized that caregivers who were unable to read or speak English would be excluded from the study. This was a difficult issue to resolve because all the measuring instruments used in the study had been standardized using the English language, and their translation would have rendered them invalid because of the absence of established psychometric properties for non-speakers of English.

A significant number of parental primary caregivers volunteered to take part in the study, but were excluded from taking part on the basis of not meeting the criteria of being able to read and speak English, and consequently deprived of the opportunity to express their needs. It is vital, given the multi-racial nature of society, for researchers to focus on specialist and minority groups within the already 'sub-group' of parental primary carers of people with learning disabilities and challenging behaviour.

In addition to developing suitable measuring instruments for non-English speakers, it is also important for researchers to start designing and developing measures to be specifically used in relation to parental primary carers of adults with learning disabilities and challenging behaviours. Many of the existing measures used in looking at the psychological impact on parental caregivers of families containing members with learning disabilities, including problem behaviours, have been standardized on the child and adolescent populations and not suitable for adults.

Further, such studies have tended to use generic measures developed for use primarily in non-learning disability populations, which have not really proved to be suitable for use in learning disability populations, particularly the group investigated in this study. This is because, as has been shown, parental primary carers of adults with learning disabilities and challenging behaviour have unique needs, which can be quite different to carers of people with other forms of learning disabilities, which need to be researched further to establish a sound knowledge base. Nonetheless, because their psychometric properties have been established, existing measures provide a good foundation and starting point for applying and adapting these instruments in use with caregivers in families containing an adult with a learning disability and exhibiting challenging behaviour.

Despite the difficulties and limitations of existing measures, this study has added to the literature on the stress and psychological impact of challenging behaviour in parental primary carers of adults with learning disabilities. Its unique contribution has been in relation to focusing specifically on the adult population and also by expanding the range of predictor variables to include factors such as personality, socio-economic factors and coping strategies, by including positive and negative outcome measures as well as service-related ones, and by an exploratory in-depth investigation of parental primary caregivers' views, needs and experiences relating to learning disability services. The study has also illustrated the urgent need for further research in this area. It is important to examine further the variables found to be significant in relation to psychological adaptation in parental primary carers of adults with learning disabilities and challenging behaviour living in their parental home.

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The University College London Hospitals

St. Martin's House,
140 Tottenham Court Road, London W1P 9LN

Telephone: 0171 380....................

Telephone: 0171 387 9300 Ext: ....

Fax: ....

The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee A Chairman: Dr F D Thompson

Please address all correspondence to:
Mrs Iwona Nowicka
Research & Development Directorate
9th Floor, St Martin's House
140 Tottenham Court Road, LONDON W1P 9LN
Tel. 0171- 380 9579 Fax 0171-380 9536

Dr R Hastings
Lecturer in Psychology
Behavioural Science Unit
Institute of Child Health
UCL
30 Guilford Street
London WC1N 1EH

14 January 1997

Dear Dr Hastings

Study No: **96/145** *(Please quote in all correspondence)*
Title: **Stress, coping and adjustment in parental primary carers of young adults with challenging behaviour**

I acknowledge the receipt of your letter of the 18th December 1996 and confirm that your study has been approved.

Yours sincerely

Iwona Nowicka
Secretary to the Ethics Committees

The University College London Hospitals

UCL HOSPITALS

University College London Hospitals is an NHS Trust incorporating The Eastman Dental Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital, The National Hospital for Neurology & Neurosurgery, The United Elizabeth Garrett Anderson Hospital and Hospital for Women, Soho, and University College Hospital. has14jan/ijn/14 January 1997

HARROW RESEARCH ETHICS COMMITTEE
(Chairman: Dr David Lubel)
Room 6BB 014
Northwick Park Hospital
Tel: 0181-869-2688
Fax: 0181-869-2174

NORTHWICK PARK & ST. MARK'S
NHS TRUST
WATFORD ROAD HARROW
MIDDLESEX HA1 3UJ

10 February 1997

Ms N Gupta
Clinical Health Psychology Dept
UCL
Gower Street
WC1E 6BT

Dear Ms Gupta

Ethical Submission No. 2283: Stress, Coping & adjustment in parental primary carers of young adults with challenging behaviour

The above project has been considered and approved by the Harrow Research Ethics Committee. It would be appreciated if, in any future correspondence relating to this project or in any entry made in case-notes about procedures undertaken in the course of this study, you would refer to it as **EC 2117.**

The Committee wishes to remind all investigators of the importance of keeping General Practitioners informed of research work affecting their patients particularly when the patient's involvement continues after discharge from hospital.

Yours sincerely

Brian Saperia
Secretary

Redbridge & Waltham Forest
Health Authority

West Wing, 713 Eastern Avenue,
Ilford, Essex IG2 7SJ

Tel: 0181-518 2299
Fax: 0181-554 3752
ECR Fax: 0181-554 4669

Ms. Nisha Gupta
Clinical Psychologist in Training
University College Hospital
Department of Clinical Health Psychology
University College London
Gower Street
LONDON WC1E 6BT

14th February 1997

Dear Ms. Gupta

re: LREC (R&WF) 77
Stress, coping and adjustment in parental primary carers of young adults with challenging behaviour

The above-mentioned research was considered by the Redbridge & Waltham Forest Local Research Ethics Committee at their meeting on the 13th February 1997.

Dr. Pat Bishop kindly attended the meeting to respond to the Committee's questions on your behalf.

I am pleased to inform you that the Committee supported the ethical aspects of this trial, subject to a few minor amendments.

The Committee was confused as to who would be contacting the subjects and it was proposed that it would be more beneficial if Dr. Bishop identified clients and wrote to them on your behalf and asked them to reply directly to you. This would mean that Dr. Bishop would not know who was participating and you would not know the identity of those not wishing to participate. Also on the diagram of the decision/procedure tree, it would be helpful if the information could refer to Nisha Gupta or "I".

May I also advise that as the Committee covers Redbridge and Waltham Forest it may be useful for you to make contact with the Service Providers of Learning Disability Services at Forest Healthcare Trust and it would be appropriate for you to inform the personnel there that you have received approval of the Local Research Ethics Committee to carry out such a study on Redbridge or Waltham Forest residents.

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jac

The Committee looks forward to seeing a report of your research findings in due course.

Yours sincerely,

LEONARD KNOX
Chairman LREC

P:\JANETTC\ANGELA1\AW125E.DOC
jac

HEAD OFFICE
99 WAVERLEY ROAD, ST. ALBANS
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Telephone: 01727 811888
Direct Line: 01727 897811
Fax: 01727 897788

WEST HERTS COMMUNITY
HEALTH NHS TRUST
LOCAL RESEARCH ETHICS
COMMITTEE

10 June 1997

Ms Nisha Gupta

Dear Ms Gupta

WHO01/97: Stress, Coping and Adjustment in Parental Primary Carers of Adults with Challenging Behaviour

Thank you for your letter of 5 June 1997 in which you detail the amendments to the above study. These amendments address the Committee's concerns and I am therefore pleased to confirm that your study has full LREC approval.

Yours sincerely

E Watford

pp **Pauline Southworth (Mrs)**
Chairman
West Herts Community Health NHS Trust
Local Research Ethics Committee

Please reply to:

Bridge
Hatfield road
Witham
Essex
CM8 1EQ

Facsimile: (01376) 532451

Telephone: (01376) 532 439

New Possibilities
Services for people
with learning difficulties

CBK/AL

14 February 1997

Ms. Nisha Gupta
Clinical Psychologist in Training
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT

Dear Ms. Gupta,

The R. & D. Forum received your Application to carry out Study on "**STRESS, COPING AND ADJUSTMENT IN PARENTAL PRIMARY CARERS OF YOUNG ADULTS WITH CHALLENGING BEHAVIOUR**".

I note that Ethical Approval has been given by U.C.L.

Please find enclosed Application Form to submit your Proposal.

On the whole, the Group were interested in your Project and would have no objections for it to be carried out within our Trust as long as you liaise with responsible Professionals within the Trust, as you are not directly employed by us.

Mrs. Janet Wilby, Community Sister, for the same area is quite interested in this field, and I would suggest that you directly liaise with her at the following address:

Mrs. Janet Wilby
Community Sister
Chelmsford Community Learning Disability Team
St. John's Hospital
Wood Street
Chelmsford
CM1 9BG

Yours sincerely,

Dictated but not signed by

Dr. C. B. Karki
CHAIRMAN OF N.P.T. RESEARCH FORUM CULYER LEAD

Copies to:

Mrs. Janet Wilby, Community Sister

Ms. Felicity Arrell
Psychology Department
Evergreen House
114 Ipswich Road
Colchester
Essex, CO4 4AA

Please reply to:

Bridge
Hatfield road
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New Possibilities
Services for people
with learning difficulties

Our Ref: CBK/BMM/cbk008

Nisha Gupta
Clinical Psychologist in Training
University College London
Sub-Department of Clinical Health Psychology
Gower Street
LONDON WC1E 6BT

26 March 1997

Dear Sir/Madam

Thank you for your letter received by me on 20 March outlining your research project which I have kept in my files.

My best wishes for the successful completion and publication of this project.

Yours faithfully

Dr C B Karki
Medical Director

New Possibilities NHS Trust, New Possibilities House, Turner Village, Turner Road, Colchester, Essex CO4 5JP
Telephone: (01206) 844840 Fax: (01206) 842301

Miss Janet Fulford RIBA Trust Chairman Mr Murray Duncanson BA MHSM Dip HSM Chief Executive

WLS 751

RIVERSIDE RESEARCH ETHICS COMMITTEE
CHELSEA & WESTMINSTER HOSPITAL
Lower Ground Floor Pharmacy Offices
369 Fulham Road London SW10 9NH
Tel: 0181 846 6855 Fax: 0181 846 6860

Ms Nisha Gupta
Clinical Psychologist in Training
Sub-Department of Clinical Health Psychology
University College
Gower Street
London WC1E 6BT

29th January 1997

Dear Ms Gupta

RREC 1268 - Stress, coping and adjustment in parental primary carers of young adults with challenging behaviour.

I am writing to inform you that the above study has been considered and approved by Chairman's Action.

Please note the following conditions which form part of this approval:

[1] **This approval is for one year only.** For projects with an expected duration of more than one year, a letter from the principal investigator will be required in order to further extend consent. This will enable the Committee to maintain a full record of research.

[2] Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee's approval.

[3] The Committee should be notified immediately of any serious adverse events or if the entire study is terminated prematurely.

[4] You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, e.g., extra work for laboratories. Approval by the Committee for your project does not remove your responsibility to negotiate such factors with your colleagues.

[5] You must ensure that nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.

Cont/2...

Cont/2..**RREC 1268 - Stress, coping and adjustment in parental primary carers of young adults with challenging behaviour.**

[6] Pharmacy must be told about any drugs and all drug trials, and must be given the responsibility of receiving and dispensing any trial drug.

[7] The Committee must be advised when a project is concluded and should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.

May I take this opportunity to wish you well in your research. However, if any doubts or problems of an unexpected nature arise, please feel free to contact me at any time.

Yours sincerely

J.N. Harcourt-Webster

J Nigel Harcourt-Webster MD FRCPath
Chairman - RREC

Seen and Approved		
Submission	22-11-96	Signed Initials: J.N.H.
Protocol		Signed Initials: J.N.H.
Information Sheet	and letter to Parents and Manager	Signed Initials: J.N.H.
Consent Form		Signed Initials: J.N.H.
Questionnaires		Signed Initials: J.N.H.
Letter of Indemnity		Signed Initials: —
CTX/DDX/Licence		Signed Initials: —

HILLINGDON

HEALTH AUTHORITY

Kirk House 97-109 High Street
Yiewsley West Drayton Middlesex UB7 7HJ
Tel: 01895 452000 Fax: 01895 452108

Direct Line 01895 452006

16 December 1996

Nisha Gupta
Clinical Psychologist in Training
University College London
Sub-Department of Clinical Health Psychology
Gower Street
London WC1E 6BT

Dear Ms Gupta

ETHICS COMMITTEE SUBMISSION 799
Stress, coping and adjustment in parental primary carers of young adults with challenging behaviour

With reference to the above submission to the Local Research Ethics Committee, I am pleased to confirm that this was approved at the Ethics Committee Meeting on 3 December 1996. You may proceed with your proposed study subject to the following conditions:-

1 Please note that permission from the carer should be sought at an early stage.

2 Please remove the reference to the Ethics Committee from the Patient Information Sheet.

3 Regarding the letter to the Managers:-

* With reference to Ms Radon please include her place of work.

* Please amend the third sentence of the second paragraph so that it reads 'I would like to interview primary parental carers of young adults who have learning disabilities with challenging behaviour.'

* Patient confidentiality must be ensured. Please ensure that the manager does not know which patients have refused or consented to the study.

4 In the letter to the parent please inform the carer that the study is unlikely to effect an immediated change in Services.

5 Please ask the parent's permission at the beginning of the study to contact their GP.

Chairwoman **Sandra Edwards**
Chief Executive **David Panter**

Printed on environmentally friendly paper

6. The patient should receive a brief summary of the report on the outcome of the study.

7. Please could you amend the Protocol as it presently contradicts the Patient Information Sheet, which states that the questionnaire would take 15-20 minutes to complete. The Protocol states that it would take 45 minutes.

8. If both parents would like to participate in the study they should both be able to take part.

9. A brief report on the study (say 1-2 sides of A4 paper) should be submitted to the Ethics Committee at the end of the project or annually in the case of an ongoing study.

10. Should you leave your current post before completing the project, the Ethics Committee will need to be advised of whether the project is to continue and the name of the practitioner who will undertake the project in future. If a project is discontinued some written information on progress to date should be deposited with the Secretary of the Committee to be kept on file.

Should you have any query about these points please do not hesitate to discuss them with me or the Chairman. In addition you may wish to refer to detailed guidance issued by the Royal College of Physicians on Ethics Committees in Medical Research, a copy is available for perusal in the Postgraduate Medical Centre Library, or we have a copy here. Also, enclosed with this letter you will find a copy of the Annex to Directive 91/507/EEC on the conduct of clinical trials.

Yours sincerely

pp

Clare Gray (Ms) - Secretary - Ethics Committee

10 November 1996

Dear Manager

Stress, coping and adjustment in parental primary carers of adults with challenging behaviour

I am writing to tell you about and ask for your participation in a research study that I am currently undertaking as a part of the Clinical Psychology training course at University College London. I have enclosed a protocol of the study, which briefly explains the purpose and nature of the research project, and highlights the ways in which local services will benefit from the study. I have also enclosed a copy of the participant information letter to be sent to families who may take part in the research.

I have spoken to Ms R, Clinical Psychologist, Learning Disabilities, who has seen the research proposal and has agreed for me to contact you. She has suggested that you may be able to identify some suitable participants for the research study. I need to interview primary parental carers of adults with learning disabilities and challenging behaviour. The defining criteria for the selection of such participants are described in more detail in the study protocol.

If you decide to help with this research, your primary role will be to identify and inform me of the total number of adults with learning disabilities in your service who are over and including the age of 18 and exhibit challenging behaviour. Subsequently, depending on rules of confidentiality within your service, I will either send or ask you to send letters to all of the parental carers of the identified adults, inviting them to participate in the research.

If you are able to give me access to names and addresses of identified families, I will send potential participants a copy of the participant information letter, requesting their participation in the research study, together with a self-addressed envelope for their reply.

If access to this information is prohibited, I will give you participant information letters with accompanying self-addressed envelopes to send to potential families. You will need to add the names of both parents, where relevant, onto the participant information letters, as I am not assuming that mothers will be the main carers. As I will need to send reminder letters to those carers who do not reply initially, the return slip of the participant information letter will be number coded. Therefore, I will ask you to make a written note of the number code for each family on a coding form. I will be happy to cover nominal costs such as postage. I have enclosed a separate decision/procedure tree of the main stages for clarity.

Could you please let me know by 30 November 1996 whether you will be able to participate in the research study. If you agree to participate, we can then arrange a time to meet and discuss the project in more detail if you wish. If you have any questions about the research study prior to making a commitment, please do not hesitate to contact me on either of the following telephone numbers: ☎0171 380 7897 or ☎0181 451 8283 (Mondays to Wednesdays).

I hope you will be able to participate in what is an interesting and useful piece of research. Just to add, when the study has been completed, a summary report of the findings will be available to each participating service upon request. I look forward to hearing from you soon.

Yours sincerely

Ms Nisha Gupta
Clinical Psychologist in Training

Ms Pippa Mundy
Head Clinical Psychologist
Community Team for Learning Disabilities, St Ann's Hospital, Haringey Healthcare NHS Trust.

Dr Richard Hastings
Lecturer in Psychology
Behavioural Sciences Unit, Institute of Child Health, University College London.

STRESS, COPING AND ADJUSTMENT IN PARENTAL PRIMARY CARERS OF ADULTS WITH CHALLENGING BEHAVIOUR

BACKGROUND TO THE STUDY

The growing philosophy of community care means that more and more people with learning disabilities, including those exhibiting challenging behaviour, are living at home with their families. The burden of care and responsibility usually falls on one main caregiver, often mothers.

In order for the needs of individuals with learning disabilities to be effectively met, and to enhance their quality of life, it is important to look at the implications of community care for primary caregivers. In particular, information is needed about the primary caregivers' stressors, coping resources, coping strategies, quality of life, and perceptions of professional services.

Although such studies have been undertaken by researchers and clinicians, they have concentrated on carers of children and a gap remains in research literature on parental primary carers of adults.

RATIONALE FDR THE STUDY

A review of the literature shows that very few studies have sought to examine the actual experiences of families caring for an adult child with learning disabilities and challenging behaviour. Furthermore, no study has attempted to understand how stressors, coping strategies, psychosocial adjustment and quality of life of primary parental carers are related to each other and with their perceptions and experiences of professional services.

The present study addresses these issues. The potential stressors to be studied are various characteristics of the adult child. Material, social, psychological and physical resources, and coping strategies will be measured. Outcome variables will focus on distress, and also on parents' satisfaction with life. This will be linked with an exploration of caregivers' perceptions, needs and experiences relating to professional services.

AIMS AND OBJECTIVES OF THE STUDY

The broad aim of the study is to gain a better understanding of the impact of challenging behaviour on parental primary caregivers and their families. We aim to develop a specific model of stress and coping in parental primary carers of adults with learning disabilities and challenging behaviour. This will enable services to understand and meet the needs of caregivers and their families more effectively. The main objective is to facilitate a shift in the focus of work in Learning Disabilities Services to prevention as opposed to crisis management.

The study will provide an insight into the nature and type of stressors, resources, coping strategies and quality of life of parental primary carers of young adults with challenging behaviour. It will attempt to identify risk and protective factors related to relatively good or problematic adjustment and functioning in caregivers. From this, we will try to map out the pathways by which a variety of psycho-social-cognitive factors may contribute to good or poor adjustment in caregivers. It is hoped this will enable clinicians and services to identify at-risk families and their needs for early intervention to reduce the risk of problems and their subsequent impact in such families.

The study also aims to explore caregivers' views, experiences and needs relating to professional services. It will examine patterns of service use, satisfaction and caregivers' future hopes and aspirations in relation to their son/daughter. It is hoped that this information will be used by Learning Disabilities Services to provide more effective and appropriate support for such families.

DEFINITION OF TERMS

An ***adult*** is defined as the person with the learning disability being over and including the age of 18.

A ***parental primary caregiver*** is defined as the person in the family who accepts the main responsibility for providing care for the adult with a learning disability and challenging behaviour.

Challenging behaviour is defined as behaviour which falls into one or more of the following categories: ***aggressive*** (eg. hitting, kicking, biting, pinching, spitting, pushing, scratching, pulling hair, grabbing); ***self-injurious*** (eg. hitting, slapping, punching, pinching, poking, pulling hair, scratching, biting); ***destructive*** (eg. deliberately throwing, sweeping and/or breaking objects); ***disruptive*** (eg. vocalising, screaming, shouting, crying, lying on floor, wetting self with awareness in place other than the toilet, smearing, non-compliance, banging, spitting); and ***stereotyped*** (eg. repetitive spinning, running, object gazing, climbing, body rocking, hand /body movements).

SAMPLE

The sample will consist of parental primary caregivers in families containing an adult with a learning disability and challenging behaviour. Participants will be identified and recruited via local services for people with learning disabilities.

METHOD

Each primary carer will be sent a letter, via local services for people with learning disabilities, explaining the purpose and nature of study. If participants agree to take part in the study, they will be given a consent form to sign and an appointment time. Each carer will be given self-administered questionnaires to complete and interviewed using a semi-structured interview schedule. Interviews will be tape-recorded for later coding and analysis.

CONFIDENTIALITY

All participants will remain anonymous. All information collected during the study will be strictly confidential and used for research purposes only. Also, all tape-recorded information will be destroyed when the study has been completed.

ETHICAL APPROVAL

Ethical approval has been granted by the joint University College London & University College Hospital's Ethic Committees for Human Research.

TIMESCALE

Interviews with carers are scheduled to take place between January 1997 and June 1997.

SUPERVISORS

Dr Richard Hastings
Lecturer in Psychology
Behavioural Sciences Unit, Institute of Child Health, University College London, 30 Guilford Street, London WC1N 1EH
☎0171 831 0975

Ms Pippa Mundy
Head Clinical Psychologist
Community Team for Learning Disabilities, St. Ann's Hospital, Haringey Healthcare NHS Trust, St Ann's Road, London N15 31H
☎0181 442 6111

If you have any further questions or would like to discuss the study in more detail please contact:

Nisha Gupta
Clinical Psychologist in Training
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT

☎0171 380 7897
☎0181 451 8283

INSTRUCTIONS

To enable me to send reminder letters to those carers who do not reply initially, each caregiver who is sent an information letter has been given an individualised number code. This is recorded at the top right hand side of the blue return slip at the end of each information letter to parental caregivers.

When sending the information letters to parental caregivers, could you please make a note of this individualised number code. Please record the name, address and number code for each caregiver in the table below.

NAME	ADDRESS	NUMBER CODE
		☐☐☐☐☐
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		☐☐☐☐☐

Decision/Procedure Tree for Managers

Do you wish to participate in research study?

YES

NO

Let Nisha Gupta know of this decision. You will not be pressured in any way to change your mind.

Step 1: Identify and inform Nisha Gupta of the total number of adults with learning disabilities in your service who are over and including the age of 18 and exhibit challenging behaviour.

Step 2: *(a) Either:*

Nisha Gupta will send potential participants a copy of the participant information letter, requesting their participation in the research study, together with a self-addressed envelope for their reply.

(b) Or:

Nisha Gupta will give you participant information letters with accompanying self-addressed envelopes to send to potential families.

Step 3: You will need to add the names of both parents, where relevant, onto the participant infomation letters, as I am not assuming that mothers will be the main carers.

Step 4: As I will need to send reminder letters to those carers who do not reply initially, the return slip of the participant information letter will be number coded. Therefore, I will ask you to make a written note of the number code for each family on a coding form.

Step 5: For those participants who do not reply initially, I will be sending reminder letters, which I will ask you to do as in Steps 2 & 3.

Step 6: Upon the study's completion, if you requested one, a summary report of the findings will be sent to you.

19 May 1997

Dear Parent(s)/Carer(s)

I am writing to let you know about some research being carried out in our area, and our service has had a request to help with this. For reasons of confidentiality, we cannot pass names and addresses on to others but we can pass on to you a request for help.

Nisha Gupta is a trainee clinical psychologist who needs some help with research she is doing about how parents cope with young adults with challenging behaviours. If you feel you would like to help her by completing her questionnaire/interview, please complete the reply slip and return it to Nisha in the stamped addressed envelope.

I hope you will be able to find the time to take part in this study. I can think of two possible benefits. Attention will be drawn to your needs as a parent coping with difficult behaviours and you may encourage a young enthusiastic psychologist to work further in this field which certainly needs work done.

Yours sincerely

Carla Ashe
Deputy Manager

18 May 1997

Dear Parent(s)/Carer(s)

Stress, coping and adjustment in parental primary carers of adults with challenging behaviour

I am writing to tell you about and ask for your participation in a research study that I am currently undertaking as part of the Clinical Psychology training course at University College London. My study looks at stress, coping and adjustment in parental primary carers, like yourself, in families containing adults with challenging behaviour living at home. The study also explores parents' views, needs and experiences relating to professional services.

I am recruiting participants from various Learning Disability Services in and around the London area, including your local service area. Your local service has agreed to send this letter to you anonymously on my behalf. Therefore, they know about this study, but are essentially independent of it. Thus, if you decide not to participate in this project, it will not affect your rights and future care in any way.

WHY IS THIS STUDY BEING CARRIED OUT?

The purpose of the study is to provide a better insight into the sources of stress, the way in which caregivers cope with stress, and the quality of life of parental primary carers of adults with learning disabilities and challenging behaviour. The study also aims to provide more information on caregivers' views, experiences and needs relating to professional services. It is hoped that this information will be used by Learning Disabilities Services to plan more effective and appropriate support for families such as yours.

WHO DO WE WANT TO PARTICIPATE?

The selection criteria for the study are that you must be a primary parental caregiver in a family containing an adult with a learning disability and exhibiting challenging behaviour. These terms are more fully explained in the next section.

WHAT DO ALL THESE TERMS MEAN?

A ***parental primary caregiver*** means the person in the family who accepts the main responsibility for providing care for the adult with a learning disability and exhibiting challenging behaviour.

An ***adult*** describes a person who is over and including the age of 18.

Challenging behaviour refers to behaviour that falls into one or more of the following categories: ***aggressive*** (eg. hitting, kicking, biting, pinching, spitting, pushing, scratching, pulling hair, grabbing); ***self-injurious*** (eg. hitting, slapping, punching, pinching, poking, pulling hair, scratching, biting); ***destructive*** (eg. deliberately throwing, sweeping or breaking objects); ***disruptive*** (eg. vocalising, screaming, shouting, crying, lying on floor, wetting self with awareness in place other than the toilet, smearing, non-compliance, banging, spitting); and ***stereotyped*** (eg. repetitive spinning, running, object glazing, climbing, body rocking, hand and body movements).

WHICH PARENT IS CHOSEN TO TAKE PART?

Research studies have shown that mothers often accept the main responsibility for providing care for children with learning disabilities. However, in some families fathers do most of the caregiving, or it is evenly divided between both parents. For this study, you have to decide which partner takes the main responsibility for providing care or, if care is evenly divided, decide which partner is to take part in the study. As this decision can be difficult, I can help you clarify and decide which partner should participate in the study before I come to see you.

WHAT DO YOU NEED TO DO?

If you agree to take part in the study, I will telephone or write to you to arrange an appointment time to meet with you in your own home or somewhere else of your choosing. I will also send you some questionnaires, which should take forty to fifty minutes to complete. These will ask you questions about your health, satisfaction with life, personal attitudes and traits, family and social relationships.

When I meet with you, I will begin by briefly reminding you about the purpose and nature of the study, and answer any questions you may have about the study and ask you to sign a written consent form. We can then go through the questionnaires, clarifying any concerns or questions you have. I will also ask you questions about your son/daughter and his/her behaviour.

After completion of the questionnaires, I would like to ask you about your personal views, needs and experiences relating to professional services. This interview will be informal, and it is intended to be helpful and supportive. Interviews will last approximately twenty minutes and, if you agree, they will be tape-recorded for later analysis. After the interview, there will be an opportunity to discuss the experience of taking part in the study and any further concerns or questions arising from this. The whole appointment will take about one and a half hours.

WHO SEES THE INFORMATION COLLECTED?

The individual identities of all participants will be known only to me. All participants will remain anonymous and on no account can anyone be individually identified from the data. Information collected during the study will be strictly confidential and used for research purposes only. Also, all tape-recorded information will be destroyed when the study has been completed.

ETHICAL APPROVAL - WHAT IS THAT?

Every research project has to be approved by an Ethics Committee. This study has been reviewed by the joint University College London & University College Hospital's Ethics Committees for Human Research, who have granted permission to carry out this study.

WHAT DO YOU GAIN?

When the study has been completed, I will send you a brief report of the main findings, which will enable you to understand the general experiences and needs of families similar to yours.

Could you please let me know whether you would be interested in taking part in this study by completing the reply slip attached to the end of this letter and returning it to me in the stamped addressed envelope provided to the above address by **Friday 20 June 1997**. If you have any concerns or questions about the research study before making a decision about whether or not to participate, please do not hesitate to contact me on ☎0181 451 8283. If you decide that you do not want to take part in this study, or to withdraw your consent at any stage, you are assured that this decision will not affect your rights and future care.

With many thanks for your help.

Yours sincerely

Ms Nisha Gupta
Clinical Psychologist in Training & Principal Investigator

Ms Pippa Mundy
Head Clinical Psychologist & Research Supervisor
Community Team for Learning Disabilities, St Ann's Hospital, Haringey Healthcare NHS Trust.
☎ 0181 442 6111

Dr Richard Hastings
Lecturer in Psychology & Research Supervisor
Behavioural Sciences Unit, Institute of Child Health, University College London.
☎ 0171 831 0975

For Office Use Only:
☐☐☐☐☐

Stress, coping and adjustment in parental primary carers of adults with challenging behaviour

by

Nisha Gupta

Clinical Psychologist in Training

Please put a √ in the box below if you ***do*** wish to take part in this study.

☐ **Yes**, I would like to take part in this research study.
Please phone and make an appointment.

☞ Please **do not forget** to give your name, address and telephone number.

Please put a ×in the box below if you ***do not*** wish to take part in this study.

☐ **No**, I would not like to take part in this research study.
Please do not contact me.
This will not affect my rights and future care.

☞ You do not have to give your name, address and telephone number.

Signature ______________________

Name ______________________

Address ______________________

____

____

Telephone Number ______________________

26 January 1997

Dear Parent/Carer

Stress, coping and adjustment in parental primary carers of adults with challenging behaviour

Thank you for participating in my research study. Further to our telephone conversation, I am writing to confirm our appointment on **Thursday 6 February at 11am** at your home.

I have enclosed a questionnaire for you to complete before the actual appointment. These ask you questions about your health, satisfaction with life, personal attitudes and traits, family and social relationships. If you have any questions or concerns about any of these questions, please do not hesitate to contact me on either of the following telephone numbers: ☎0171 380 7897 or ☎0181 451 8283 (Mondays to Wednesdays). However, there will be an opportunity to go over these questionnaires when we meet.

Just to quickly reiterate, when I meet with you, I will begin by briefly reminding you about the purpose and nature of the study, and answer any questions you may have about the study and ask you to sign a written consent form. We can then go through the questionnaires, clarifying any concerns or questions you have. I will also ask you questions about you, your family and your son/daughter and his/her behaviour.

After completion of the questionnaires and additional demographic material, I would like to ask you about your personal views, needs and experiences relating to professional services. This interview will be informal, and it is intended to be helpful and supportive. Interviews will last approximately twenty minutes and, if you agree, they will be tape-recorded for later analysis. After the interview, there will be an opportunity to discuss the experience of taking part in the study and any further concerns or questions arising from this. The whole appointment will take about one and a half hours.

I look forward to meeting you.

Yours sincerely

Ms Nisha Gupta
Clinical Psychologist in Training

STRESS, COPING AND ADJUSTMENT IN PARENTAL PRIMARY CARERS OF ADULTS WITH CHALLENGING BEHAVIOUR

QUESTIONNAIRE TO BE COMPLETED BY PARENTAL PRIMARY CAREGIVER

Please answer the following questions as honestly and completely as you can. Read each question carefully. It is important that you try to answer ALL the questions. Work quickly, and don't spend too much time over any question; we want your first reaction, not a long-drawn out thought process. There are no right or wrong answers. The whole questionnaire should take about forty minutes to complete. Remember, all your answers are confidential.

SECTION A

The questions in this section ask about your general health and well being. We should like to know if you have had any medical complaints and how your health has been in general, over the past few weeks. Please answer ALL the questions simply by circling the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

HAVE YOU RECENTLY...

A1	**been feeling perfectly well and in good health**	*Better than usual*	*Same as usual*	*Worse than usual*	*Much worse than usual*
A2	**been feeling in need of a good tonic**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
A3	**been feeling run down and out of sorts**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
A4	**felt that you are ill**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
A5	**been getting any pains in your head**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
A6	**been getting a feeling of tightness or pressure in your head**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
A7	**been having hot or cold spells**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*

HAVE YOU RECENTLY...

B1	**lost much sleep over worry**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
B2	**had difficulty in staying asleep once you are off**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
B3	**felt constantly under strain**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
B4	**been getting edgy and bad-tempered**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
B5	**been getting scared or panicky for no good reason**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
B6	**found everything getting on top of you**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
B7	**been feeling nervous and strung-up all the time**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*

PTO

HAVE YOU RECENTLY...

C1	**been managing to keep yourself busy and occupied**	*More so than usual*	*Same as usual*	*Rather less than usual*	*Much less than usual*
C2	**been taking longer over the things you do**	*Quicker than usual*	*Same as usual*	*Longer than usual*	*Much longer than usual*
C3	**felt on the whole you were doing things well**	*Better than usual*	*About the same*	*Less well than usual*	*Much less well*
C4	**been satisfied with the way you've carried out your task**	*More satisfied*	*About same as usual*	*Less satisfied than usual*	*Much less satisfied*
C5	**felt that you are playing a useful part in things**	*More so than usual*	*Same as usual*	*Less useful than usual*	*Much less useful*
C6	**felt capable of making decisions about things**	*More so than usual*	*Same as usual*	*Less so than usual*	*Much less capable*
C7	**been able to enjoy your normal day-to-day activities**	*More so than usual*	*Same as usual*	*Less so than usual*	*Much less than usual*

HAVE YOU RECENTLY...

D1	**been thinking of yourself as a worthless person**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
D2	**felt that life is entirely hopeless**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
D3	**felt that life isn't worth living**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
D4	**thought of the possibility that you might make away with yourself**	*Definitely not*	*I don't think so*	*Has crossed my mind*	*Definitely have*
D5	**found at times you couldn't do anything because your nerves were too bad**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
D6	**found yourself wishing you were dead and and away from it all**	*Not at all*	*No more than usual*	*Rather more than usual*	*Much more than usual*
D7	**found that the idea of taking your own life kept coming into your mind**	*Definitely not*	*I don't think so*	*Has crossed my mind*	*Definitely has*

PTO

SECTION B

This section contains some statements about beliefs and attitudes people may or may not have. Thinking about your own beliefs and attitudes of the kind described below, please indicate how you typically feel by circling one number for each of the items presented below, using the scale presented.

What happens to me is my own doing.	***Strongly disagree*** **1**	**2**	**3**	**4**	***Strongly agree*** **5**
Many of the unhappy things in people's lives are partly due to bad luck.	***Strongly disagree*** **1**	**2**	**3**	**4**	***Strongly agree*** **5**
Many times I feel that I have little influence over the things that happen to me.	***Strongly disagree*** **1**	**2**	**3**	**4**	***Strongly agree*** **5**
Getting people to do the right things depends upon ability; luck has nothing to do with it.	***Strongly disagree*** **1**	**2**	**3**	**4**	***Strongly agree*** **5**
Getting a good job depends mainly on being in the right place at the right time.	***Strongly disagree*** **1**	**2**	**3**	**4**	***Strongly agree*** **5**
When I make plans, I am almost certain that I can make them work.	***Strongly disagree*** **1**	**2**	**3**	**4**	***Strongly agree*** **5**

SECTION C

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is true or false as it applies to you personally. Please circle either True or False for each statement.

1	I like to gossip at times.	***True***	***False***
2	There have been occasions when I took advantage of someone.	***True***	***False***
3	I'm always willing to admit it when I make a mistake.	***True***	***False***
4	I always try to practice what I preach.	***True***	***False***
5	I sometimes try to get even rather than forgive and forget.	***True***	***False***
6	At times I have really insisted on having things my own way.	***True***	***False***
7	There have been occasions when I felt like smashing things.	***True***	***False***
8	I never resent being asked to return a favour.	***True***	***False***
9	I have never been irked when people expressed ideas very different from my own.	***True***	***False***
10	I have never deliberately said something that hurt someone's feelings.	***True***	***False***

PTO

SECTION D

*The items below concern how you may cope with your son or daughter's challenging behaviour. Over the last month, thinking of any difficult situations you have had to deal with in relation to you son's or daughter's behaviour, read each item and think about how much you have tended to use each of these to cope. Then respond to each of the items by circling one of the following response choices: (1) I usually **don't** do this **at all** (2) I usually do this **a little bit** (3) I usually do this a **medium amount** (4) I usually do this a **lot**. Please try to respond to each item **separately in your mind from each other item.***

		Don't use at all	***Use a little bit***	***Use a medium amount***	***Use a lot***
1	I try to grow as a person as a result of the experience.	0	1	2	3
2	I turn to work or other substitute activities to take my mind off things.	0	1	2	3
3	I get upset and let my emotions out.	0	1	2	3
4	I try to get advice from someone about what to do.	0	1	2	3
5	I concentrate my efforts on doing something about it.	0	1	2	3
6	I say to myself "this isn't real".	0	1	2	3
7	I put my trust in God.	0	1	2	3
8	I laugh about the situation.	0	1	2	3
9	I admit to myself that I can't deal with it, and quit trying.	0	1	2	3
10	I restrain myself from doing anything too quickly.	0	1	2	3
11	I discuss my feelings with someone.	0	1	2	3
12	I use alcohol or drugs to make myself feel better.	0	1	2	3
13	I get used to the idea that it happened.	0	1	2	3
14	I talk to someone to find out more about the situation.	0	1	2	3
15	I keep myself from getting distracted by other thoughts or activities.	0	1	2	3
16	I daydream about things other than this.	0	1	2	3
17	I get upset, and am really aware of it.	0	1	2	3
18	I seek God's help.	0	1	2	3
19	I make a plan of action.	0	1	2	3
20	I make jokes about it.	0	1	2	3
21	I accept that this has happened and that it can't be changed.	0	1	2	3
22	I hold off doing anything about it until the situation permits.	0	1	2	3
23	I try to get emotional support from friends and relatives.	0	1	2	3
24	I just give up trying to reach my goal.	0	1	2	3
25	I take additional action to try to get rid of the problem.	0	1	2	3
26	I try to lose myself for a while by drinking alcohol or taking drugs.	0	1	2	3
27	I refuse to believe that it has happened.	0	1	2	3
28	I let my feelings out.	0	1	2	3
29	I try to see it in a different light, to make it seem more positive.	0	1	2	3
30	I talk to someone who could do something concrete about the problem.	0	1	2	3

PTO

		Don't use at all	*Use a little bit*	*Use a medium amount*	*Use a lot*
31	I sleep more than usual.	0	1	2	3
32	I try to come up with a strategy about what to do.	0	1	2	3
33	I focus on dealing with this problem, and if necessary let other things slide a little.	0	1	2	3
34	I get sympathy and understanding from someone.	0	1	2	3
35	I drink alcohol or take drugs, in order to think about it less.	0	1	2	3
36	I kid around about it.	0	1	2	3
37	I give up the attempt to get what I want.	0	1	2	3
38	I look for something good in what is happening.	0	1	2	3
39	I think about how I might best handle the problem.	0	1	2	3
40	I pretend that it hasn't really happened.	0	1	2	3
41	I make sure not to make matters worse by acting too soon.	0	1	2	3
42	I try hard to prevent other things from interfering with my efforts at dealing with this.	0	1	2	3
43	I go to movies or watch TV, to think about it less.	0	1	2	3
44	I accept the reality of the fact that it happened.	0	1	2	3
45	I ask people who have had similar experiences what they did.	0	1	2	3
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot.	0	1	2	3
47	I take direct action to get around the problem.	0	1	2	3
48	I try to find comfort in my religion.	0	1	2	3
49	I force myself to wait for the right time to do something.	0	1	2	3
50	I make fun of the situation.	0	1	2	3
51	I reduce the amount of effort I'm putting into solving the problem.	0	1	2	3
52	I talk to someone about how I feel.	0	1	2	3
53	I use alcohol or drugs to help me through it.	0	1	2	3
54	I learn to live with it.	0	1	2	3
55	I put aside other activities in order to concentrate on this.	0	1	2	3
56	I think hard about what steps to take.	0	1	2	3
57	I act as though it hasn't even happened.	0	1	2	3
58	I do what has to be done, one step at a time.	0	1	2	3
59	I learn something from the experience.	0	1	2	3
60	I pray more than usual.	0	1	2	3

PTO

SECTION E

*The questions in this section ask **you** about your relationship with your partner/spouse. Please fill out the items by placing a tick [√] next to or under the appropriate answer.*

1 **In your family who has made the decisions in each of the following areas?**

	Almost always male spouse/partner	*Shared equally*	*Almost always female spouse/partner*	*Does not apply*
a) where you live	☐	☐	☐	☐
b) whether female partner works	☐	☐	☐	☐
c) how to handle the children	☐	☐	☐	☐
d) when to spend time with relatives and in laws	☐	☐	☐	☐
e) how to spend money	☐	☐	☐	☐

2 **When you and your spouse/partner disagree, does it usually end that:**

☐ partner/spouse give in
☐ disagreement is avoided or unresolved and decisions are made separately
☐ you reach a compromise that you both like

3 **In the past six months, how often have you and your partner/spouse agreed on ways of handling situations involving your children?**

	Always	*Usually*	*Sometimes*
a) praising the good things they do	☐	☐	☐
b) what their responsibilities should be	☐	☐	☐
c) when or how to discipline them	☐	☐	☐
d) sharing the responsibility of their care	☐	☐	☐

4 **Over the last six months, have you been getting on each other's nerves around the house?**

☐ rarely ☐ occasionally ☐ often

5 **Have there been any problems that have caused serious difficulties in your relationship?**

☐ none ☐ one or two ☐ three or more

6 **How satisfied are you with your ability as a couple to talk over and resolve your differences?**

☐ very satisfied ☐ moderately satisfied ☐ dissatisfied

7 **In the past month how much tension or quarrelling is there between you and your partner/spouse?**

☐ very little ☐ a moderate amount ☐ a great deal

8 **Do you tell your partner/spouse about things that are on your mind - like what is worrying you, things that make you feel unsure of yourself or problems that friends have shared with you?**

☐ rarely ☐ usually ☐ always

9 Do you ever wish you had not "got together" with your present partner/spouse?

☐ rarely ☐ occasionally ☐ frequently

10 In the past two years have you been separated because of conflict?

☐ No ☐ Yes

11 In the past two years have any of your quarrels led to physical violence and injury to each other?

☐ No ☐ Yes

If yes,

Did you seek medical treatment? ☐ Yes ☐ No
Did you involve the police or other authority ☐ Yes ☐ No

12 How happy are you with the way you and your partner/spouse handle the following aspects of your family life?

	Always happy	*Usually happy*	*Seldom happy*	*Does not apply*
a) talking with each other	☐	☐	☐	☐
b) showing affection	☐	☐	☐	☐
c) trusting each other	☐	☐	☐	☐
d) having sex	☐	☐	☐	☐
e) going out with the kids	☐	☐	☐	☐
f) spending time with relatives and in-laws	☐	☐	☐	☐
g) spending time with the children	☐	☐	☐	☐
h) managing money	☐	☐	☐	☐
I) sharing the responsibilities of your home	☐	☐	☐	☐

13 Most couples experience different degrees of happiness at different times in their relationship. The questions below concern your general satisfaction with your relationship as it has been for you in the past year.

	Almost always happy	*Happy most of the time*	*Hardly ever happy*
a) everything considered, how happy are you in your relationship	☐	☐	☐
b) everything considered, how happy do you think your partner/spouse is in your relationship?	☐	☐	☐
c) is time spent with your partner/ spouse happy for you?	☐	☐	☐
d) how do you think your partner/ spouse feels about time spentwith you?	☐	☐	☐

SECTION F

Here are some questions regarding the way you behave, feel and act. After each question is a space for answering "YES" or "NO". Try to decide whether "YES" or "NO" represents your usual way of acting or feeling. Then put a cross in the circle under the column headed "YES" or "NO".

		YES	NO
1	Do you like plenty of excitement and bustle around you?	○	○
2	Have you often got a restless feeling that you want something but you do not know what?	○	○
3	Do you nearly always have a "ready answer" when people talk to you?	○	○
4	Do you sometimes feel happy, sometimes sad, without any real reason?	○	○
5	Do you usually stay in the background at parties and "get-togethers"?	○	○
6	As a child, did you always do as you were told immediately and without grumbling?	○	○
7	Do you sometimes sulk?	○	○
8	When you are drawn into a quarrel, do you prefer to "have it out" to being silent, hoping things will blow over?	○	○
9	Are you moody?	○	○
10	Do you like mixing with people?	○	○
11	Have you often lost sleep over your worries?	○	○
12	Do you sometimes get cross?	○	○
13	Would you call yourself happy-go-lucky?	○	○
14	Do you often make up your mind too late?	○	○
15	Do you like working alone?	○	○
16	Have you often felt listless and tired for no good reason?	○	○
17	Are you rather lively?	○	○
18	Do you sometimes laugh at a dirty joke?	○	○
19	Do you often feel "fed-up"?	○	○
20	Do you feel uncomfortable in anything but everyday clothes?	○	○
21	Does your mind often wander when you are trying to attend closely to something?	○	○
22	Can you put your thoughts into words quickly?	○	○
23	Are you often "lost in thought"?	○	○
24	Are you completely free from prejudice of any kind?	○	○
25	Do you like practical jokes?	○	○
26	Do you often think of your past?	○	○
27	Do you very much like good food?	○	○
28	When you get annoyed, do you need someone friendly to talk to about it?	○	○
29	Do you mind selling things or asking people for money for some good cause?	○	○
30	Do you sometimes boast a little?	○	○
31	Are you touchy about some things?	○	○

PTO

		YES	NO
32	Would you rather be at home on your own than go to a boring party?	○	○
33	Do you sometimes get so restless that you cannot sit long in a chair?	○	○
34	Do you like planning things carefully, well ahead of time?	○	○
35	Do you have dizzy turns?	○	○
36	Do you *always* answer a personal letter as soon as you can after you have read it?	○	○
37	Can you usually do things better by figuring them out alone than by talking to others about it?	○	○
38	Do you ever get short of breath without having done heavy work?	○	○
39	Are you an easy-going person, not generally bothered about having everything "just-so"?	○	○
40	Do you suffer from "nerves"?	○	○
41	Would you rather plan things than do things?	○	○
42	Do you sometimes put off until tomorrow what you ought to do today?	○	○
43	Do you get nervous in places like lifts, trains or tunnels?	○	○
44	When you make new friends, is it usually *you* who makes the first move, or does the inviting?	○	○
45	Do you get very bad headaches?	○	○
46	Do you generally feel that things will sort themselves out and come right in the end somehow?	○	○
47	Do you find it hard to fall asleep at bedtime?	○	○
48	Have you sometimes told lies in your life?	○	○
49	Do you sometimes say the first thing that comes into your head?	○	○
50	Do you worry too long after an embarrassing experience?	○	○
51	Do you usually keep "yourself to yourself" except with very close friends?	○	○
52	Do you often get into a jam because you do things without thinking?	○	○
53	Do you like cracking jokes and telling funny stories to your friends?	○	○
54	Would you rather win than lose a game?	○	○
55	Do you often feel self-conscious when you are with superiors?	○	○
56	When the odds are against you, do you still usually think it worth taking a chance?	○	○
57	Do you often get "butterflies in your tummy" before an important occasion?	○	○

PTO

SECTION G

Listed below are sources that often times are helpful to members of families raising a son/daughter with a learning disability. The questions in this section ask you to indicate how helpful each source is to ***your family****. Please* ***circle*** *the response that best describes how helpful the sources have been to your family during the past* ***3 to 6 months****.* ***Cross out*** *any sources of help that have not been available to your family during this period of time.*

		Not Available	*Not At All Helpful*	*Sometimes Helpful*	*Generally Helpful*	*Very Helpful*	*Extremely Helpful*
1	My parents	NA	0	1	2	3	4
2	My partner's/spouse's parents	NA	0	1	2	3	4
3	My relatives/kin	NA	0	1	2	3	4
4	My partner/spouse's relatives/kin	NA	0	1	2	3	4
5	My partner/spouse	NA	0	1	2	3	4
6	My friends	NA	0	1	2	3	4
7	My partner's/spouse's friends	NA	0	1	2	3	4
8	My own children	NA	0	1	2	3	4
9	Other parents	NA	0	1	2	3	4
10	Co-workers	NA	0	1	2	3	4
11	Parent groups	NA	0	1	2	3	4
12	Social groups/clubs	NA	0	1	2	3	4
13	Church	NA	0	1	2	3	4
14	My family or child's GP	NA	0	1	2	3	4
15	Professional helpers (social workers, therapists, teachers, etc.)	NA	0	1	2	3	4
16	Professional agencies (public health, social services, mental health, etc.)	NA	0	1	2	3	4
17	School/day care centre	NA	0	1	2	3	4
18	Management programmes for your son/daughter's challenging behaviour	NA	0	1	2	3	4
19	Other (eg. previous partner, previous partner's family). Please describe and rate each additional significant source of support.						
	------------------------------------	NA	0	1	2	3	4
	------------------------------------	NA	0	1	2	3	4
	------------------------------------	NA	0	1	2	3	4
	------------------------------------	NA	0	1	2	3	4

SECTION H

This section asks you some questions about your son/daughter's behaviour. Please rate your son/daughter's behaviour for the last four weeks. For each item, decide whether the behaviour is a problem and circle the appropriate number:

0 = not at all a problem
1 = the behaviour is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

When judging your son/daughter's behaviour, please keep the following points in mind:

(a) Take relative ***frequency*** into account for each behaviour specified. For example, if your son/daughter averages more temper outbursts than most other people with learning disabilities you know or most other people, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviours, such as non-compliance, would probably have to occur more frequently to merit an extreme rating.

(b) If you have access to this information, consider the experiences of other care providers with your son/daughter. If your son/daughter has problems with others but not with you, try to take the whole picture into account.

(c) Try to consider whether a given behaviour interferes with his/her ***development, functioning, or relationships***. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

Do not spend too much time on each item - your first reaction is usually the right one.

1	Excessively active at home, school, work, or elsewhere	0	1	2	3
2	Injures self on purpose	0	1	2	3
3	Listless, sluggish, inactive	0	1	2	3
4	Aggressive to other children or adults (verbally or physically)	0	1	2	3
5	Seeks isolation from others	0	1	2	3
6	Meaningless, recurring body movements	0	1	2	3
7	Boisterous (inappropriately noisy and rough)	0	1	2	3
8	Screams inappropriately	0	1	2	3
9	Talks excessively	0	1	2	3
10	Temper tantrums/outbursts	0	1	2	3

11	Stereotyped behaviour; abnormal, repetitive movements	0	1	2	3
12	Preoccupied; stares into space	0	1	2	3
13	Impulsive (acts without thinking)	0	1	2	3
14	Irritable and whiny	0	1	2	3
15	Restless, unable to sit still	0	1	2	3
16	Withdrawn; prefers solitary activities	0	1	2	3
17	Odd, bizarre in behaviour	0	1	2	3
18	Disobedient; difficult to control	0	1	2	3
19	Yells at inappropriate times	0	1	2	3
20	Fixed facial expression; lacks emotional responsiveness	0	1	2	3

---

0 = not at all a problem
1 = the behaviour is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

21	Disturbs others	0	1	2	3
22	Repetitive speech	0	1	2	3
23	Does nothing but sit and watch others	0	1	2	3
24	Uncooperative	0	1	2	3
25	Depressed mood	0	1	2	3
26	Resists any form of physical contact	0	1	2	3
27	Moves or rolls head back and forth repetitively	0	1	2	3
28	Does not pay attention to instructions	0	1	2	3
29	Demands must be met immediately	0	1	2	3
30	Isolates himself/herself from other children or adults	0	1	2	3

31	Disrupts group activities	0	1	2	3
32	Sits or stands in one position for a long time	0	1	2	3
33	Talks to self loudly	0	1	2	3
34	Cries over minor annoyances and hurts	0	1	2	3
35	Repetitive hand, body, or head movements	0	1	2	3
36	Mood changes quickly	0	1	2	3
37	Unresponsive to structured activities (does not react)	0	1	2	3
38	Does not stay in seat (eg. during lesson or training periods, meals, etc.)	0	1	2	3
39	Will not sit still for any length of time	0	1	2	3
40	Is difficult to reach, contact, or get through to	0	1	2	3

41	Cries and screams inappropriately	0	1	2	3
42	Prefers to be alone	0	1	2	3
43	Does not try to communicate by words or gestures	0	1	2	3
44	Easily distractible	0	1	2	3
45	Waves or shakes the extremities repeatedly	0	1	2	3
46	Repeats a word or phrase over and over	0	1	2	3
47	Stamps feet or bangs objects or slams doors	0	1	2	3
48	Constantly runs or jumps around the room	0	1	2	3
49	Rocks body back and forth repeatedly	0	1	2	3
50	Deliberately hurts himself/herself	0	1	2	3

51	Pays no attention when spoken to	0	1	2	3
52	Does physical violence to self	0	1	2	3
53	Inactive, never moves spontaneously	0	1	2	3
54	Tends to be excessively active	0	1	2	3
55	Responds negatively to affection	0	1	2	3
56	Deliberately ignores directions	0	1	2	3
57	Has temper outbursts or tantrums when he/she does not get own way	0	1	2	3
58	Shows few social reactions to others	0	1	2	3

PTO

SECTION I

Finally we would like to know about your life situation. When you take everything into consideration (your child, your adult life, etc.) how would you describe your ***current*** *life situation? Please circle one of the following categories:*

1 Things are very good
2 Things are fairly good
3 Things are OK - not bad and not good
4 Things are fairly bad
5 Things are very bad

☞ THIS IS THE END OF THE QUESTIONNAIRE ☜

Please have the completed questionnaire ready for your appointment with Nisha Gupta

"THANK YOU VERY MUCH FOR YOUR TIME, HELP AND CO-OPERATION"

CONSENT FORM

Study: ***Stress, coping and adjustment in parental primary carers of adults with challenging behaviour***

Researcher: ***Nisha Gupta, University College London***

☞ I have read the information letter concerning the study about "Stress, coping and adjustment in parental primary carers of adults with challenging behaviour".

☞ The study has been explained to me and my questions concerning this study have also been answered by the researcher, Nisha Gupta.

☞ I understand what will be required of me if I agree to take part in the study.

☞ I understand that I can refuse to answer any questions and that I can stop being in the study at any time without it affecting my rights and future care.

☞ I also understand that any information that I give will be kept in confidence and used for research purposes only.

☞ I agree to take part in this study.

Name of Caregiver ______________________

Signature of Caregiver ______________________

Date ______________________

Name of Researcher ______________________

Signature of Researcher ______________________

Date ______________________

SEMI-STRUCTURED INTERVIEW SCHEDULE

PART I

I am going to start by asking you some questions about you, your son/daughter who has the learning disability and exhibits challenging behaviour, and your family. I would like you to answer them as accurately as you can.

1 **Gender of parental primary carer**
☐ Female ☐ Male

2 **Age last birthday of parental primary carer**
☐☐ years

3 **Are you currently living with a partner/ spouse?**
☐ Yes ☐ No

4 **How would you describe your marital status?**
☐ Single ☐ Cohabiting
☐ Married ☐ Divorced
☐ Widowed ☐ Separated

5 **How many dependents do you care for at home (including children, older relatives, etc.)?**
☐

6 **Out of the following, how would you describe your position in relation to home ownership?**
☐ Owner Occupied ☐ Rented from LA
☐ Privately rented ☐ Other ....

7 **How would you describe your ethic status?**
☐ White ☐ Pakistani
☐ Black Caribbean ☐ Bangladeshi
☐ Black African ☐ Chinese
☐ Back Other ☐ Asian Other
☐ Indian ☐ Other ....

8 **Which of the following most accurately reflects the level of education you have achieved?**
☐ No formal qualification
☐ GCSE/O'levels or equivalent
☐ 'A' levels/HNC or equivalent
☐ HND or equivalent
☐ Polytechnic/University degree
☐ Other ....

9 **What type of service is used or attended daily by your son/daughter?**
☐ Adult Training Centre ☐ Day Centre
☐ School ☐ Other ....

10 **Do you own or have a car?**
☐ Yes ☐ No

11 **Parental status of parental primary carer**
☐ Natural ☐ Foster ☐ Adoptive

12 **What is the chronological age of your son/daughter with the learning disability**
☐☐ years

13 **Gender of the young adult with the disability**
☐ Female ☐ Male

14 **What is the position in the family of your son/ daughter with the learning disability?**
☐ Only ☐ Eldest ☐ Youngest
☐ Middle ☐ Multiple

15 **Does your son/daughter have other disabilities?**

☐ Yes ☐ No

If yes, what are they?

☐ Physical ☐ Sensory

☐ Learning ☐ Other ....

16 **If your son/daughter has a formal diagnosis, can you tell me what it is (e.g. Down's, Cerebral palsy, spina bifida, autism)?**

☐ .... ☐ ....

☐ .... ☐ ....

17 **Does your son/daughter have any other medical problems?**

☐ Yes ☐ No

If yes, what are they?

☐ .... ☐ ....

☐ .... ☐ ....

18 **Current medications** **Dosage**

____

____

____

____

19 **Status and nature of employment of parental primary carer**

☐ Yes ....

☐ No ....

(Socio-economic status to be coded later)

20 **Status and nature of employment of partner/spouse**

☐ Yes ....

☐ No ....

(Socio-economic status to be coded later)

21 **Parental status of partner/spouse**

☐ Natural ☐ Foster ☐ Adoptive

22 **Age last birthday of partner/spouse**

☐ ☐ years

23 **How would you describe your partner/spouse's ethnic status?**

☐ White ☐ Pakistani

☐ Black Caribbean ☐ Bangladeshi

☐ Black African ☐ Chinese

☐ Back Other ☐ Asian Other

☐ Indian ☐ Other ....

24 **Which of the following most accurately reflects the level of education your partner/spouse has achieved?**

☐ No formal qualification

☐ GCSE/O'levels or equivalent

☐ 'A' levels/HNC or equivalent

☐ HND or equivalent

☐ Polytechnic/University degree

☐ Other ....

25 **Number of children in nuclear family**

☐

26 **Number of children living at home**

☐

PART II

I am now going to ask you about the nature and severity of your son/daughter's learning disability.

1. Mobility

0 Nonmobile, or needs help walking on flat
1 Needs help upstairs, but walks on flat without human aid
2 Needs help only because blind or has fits
3 Walks unaided everywhere without human aid

Scoring
Nonmobile = rating 0

2. Feeding/washing/dressing

a Feeding
0 Not at all
1 With help
2 Without help

(Rate 2 if s/he eats without undue mess, in reasonable time if left alone and food does not have to be specially prepared after it has been cooked)

b Washing
0 Not at all
1 With help
2 Without help

(Rate 2 if a man can wash himself, but has to be shaved)

c Dressing
0 Not at all
1 With help
2 Without help

Scoring
Feeding/washing/dressing score = sum of ratings on a. to c.

3. Continence *(Include wetting/soiling due to fits)*

a Wetting nights
0 Five to seven times per week
1 Three or four times per week
2 Twice weekly
3 Once weekly or less
4 Never

b Soiling nights
0 Five to seven times per week
1 Three or four times per week
2 Twice weekly
3 Once weekly or less
4 Never

c **Wetting days**

0 Five to seven times per week
1 Three or four times per week
2 Twice weekly
3 Once weekly or less
4 Never

d **Soiling days**

0 Five to seven times per week
1 Three or four times per week
2 Twice weekly
3 Once weekly or less
4 Never

Scoring
Continence score = sum of ratings on a. to d.
Severe incontinence = rating 0, 1 in a. and/or 0, 1, 2 in b. and/or c. and/or d.

4. Quality of social interaction

(Choose one of the following ratings which best describes the person. The informant should consider the behaviour shown towards people the person does not know well. Some very aloof retarded adults and children may become attached to someone who works closely with them, but this section is concerned with social interaction with acquaintances and people in general. Rate on the general behaviour, not the occasional moments of interaction that are better than average.)

0 Does not interact; aloof and indifferent.
1 Interacts to obtain needs, otherwise indifferent.
2 Responds to and may initiate physical contact only, including rough and tumble games, chasing, cuddling, etc.
3 Generally does not initiate, but responds to social, not just physical, contact, if others, including age peers, make approaches. Joins in passively eg. as baby in game of mothers and fathers, or, for adults, in adult social situations. Tries to copy but with little understanding. Shows some pleasure in passive role.
4 Makes social approaches actively, but these are usually one sided, inappropriate, naive, peculiar or bizarre. The behaviour is not modified according to needs, interests and responses of persons approached.
5 Shy, but social contacts appropriate for mental age with well known people, including age peers. Also use for children who refuse to talk to adults, but interact with other children. For older children and adults, this rating can be used for those who are not gregarious, but who can interact appropriately with people they like. Also use for those who have periods of social withdrawal due to psychiatric illness or moodiness, but who interact normally between.
6 Social contacts appropriate for mental age with children and adults. Looks up with interest and smiles when approached. Responds to the ideas and interests of people of similar mental age and contributes to the interaction. Nonmobile people without speech can show social interest through gestures, facial expression and communicating by means of eye contact and eye pointing.

Scoring
Aloof = ratings 0 to 2
Passive = rating 3
Odd = rating 4
Socially impaired = ratings 0 to 4
Sociable = ratings 5 or 6

5. Communication

a Understanding communication (speech, gesture, drawing, etc.)

- 0 Little or nothing.
- 1 Understands a few simple commands (eg. come here, sit down).
- 2 Understands instructions related to practical needs.
- 3 Understands comments, questions and instructions related to personal needs and experiences (eg. did you enjoy your trip to the zoo?).
- 4 Understands information about things outside his immediate experience (eg. if told a nurse in another ward is leaving).

b Using communication (speech, gesture, drawing, etc.)

- 0 Little or nothing, or meaningless echolia
- 1 Uses a few words or signs (eg. hello, bye-bye, drink)
- 2 Uses words or signs for practical needs
- 3 Uses words or signs to comment on own personal experience (eg. tells people s/he has new clothes, that s/he has been on an outing, that someone has done something wrong)
- 4 Can converse, in words or signs, about things outside his own personal experience (eg. makes comments about items in the news, or about the family of someone s/he knows)

Scoring
Communication score = sum of ratings on a. and b.
Cannot indicate simple needs = rating 0 or 1 in b.

6. Vision *(Rate with spectacles if worn)*

- 0 Minimal/no vision
- 1 Poor vision
- 2 Normal

7. Hearing *(Rate with hearing aid if worn)*

- 0 Minimal/no hearing
- 1 Poor hearing
- 2 Normal

8. Domestic skills *(Laying tables, washing up, cooking, bed making, etc.)*

- 0 None
- 1 Sometimes with supervision
- 2 Works well with little or no supervision

Scoring
Domestic skills score = rating as above

9. Reading/writing/counting

a Reading

- 0 Has no understanding of written words
- 1 Can recognise own name when written
- 2 Can match words to pictures
- 3 Can recognise up to 10 familiar words
- 4 Can read and understand simple first reading books
- 5 Can read and understand books for children aged 7+

b **Writing**
0 None
1 Can write some letters by copying
2 Can write some words by copying
3 Can write some letters without copying
4 Can write a few simple words without copying
5 Can write 12 or more words without copying
6 Can write a short letter on own initiative

c **Counting and money**
0 Nothing, or can say 1,2,3, with little or no meaning
1 Can at least sort out 4 spoons, 3 sheets, 5 plates, etc.
2 Understands money values, makes small purchase

Scoring
Reading/writing/counting score = sum of ratings on a. to c

PART III

Out of the challenging behaviours that your son/daughter exhibits, which specific behaviour do you find the most difficult to deal with? I would like to ask you some questions about your understanding of this specific behaviour that you mentioned.

Behaviour Description ______________________________

	ITEM	RESPONSE						
1	**Would the behaviour occur continuously, over and over, if this person was left alone for long periods of time? (For example, several hours.)**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
2	**Does the behaviour occur following a request to perform a difficult task?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
3	**Does the behaviour seem to occur in response to your talking to other persons in the room?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
4	**Does the behaviour ever occur to get a toy, food or activity that this person has been told that he or she can't have?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
5	**Would the behaviour occur repeatedly, in the same way, for very long periods of time, if no one was around ? (For example, rocking back and forth for over an hour.)**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
6	**Does the behaviour occur when any request is made of this person?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6

7	**Does the behaviour occur whenever you stop attending to this person?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
8	**Does the behaviour occur when you take away a favourite toy, food or activity?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
9	**Does it appear to you that this person enjoys performing the behaviour ? (It feels, tastes, looks, smells, and/or sounds pleasing.)**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
10	**Does this person seem to do the behaviour to upset or annoy you when you are trying to get him or her to do what you ask?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
11	**Does this person seem to do the behaviour to upset or annoy you when you are not paying attention to him or her? (For example, if you are sitting in a separate room, interacting with another person.)**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
12	**Does the behaviour stop occurring shortly after you give this person the toy, food or activity he or she has requested?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
13	**When the behaviour is occurring, does this person seem calm and unaware of anything else going on around him or her?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
14	**Does the behaviour stop occurring shortly after (one to five minutes) you stop working or making demands of this person?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
15	**Does this person seem to do the behaviour to get you to spend some time with him or her?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6
16	**Does this behaviour seem to occur when this person has been told that he or she can't do something he or she had wanted to do?**	Never 0	Almost Never 1	Seldom 2	Half the time 3	Usually 4	Almost Always 5	Always 6

PART IV

I would now like to ask your opinions, perceptions and needs of professional services for people with learning disabilities. These will help us to understand your views and the types of needs you have to subsequently enable better planning and provision of services. If you agree, I would like to tape record this part of the interview for later coding and analysis, but all tapes will be destroyed upon study's completion.

May I? ☐ **Yes** ☐ **No**

SECTION A: USE OF GENERAL LEARNING DISABILITY SERVICES

I will begin by asking you about your general experience and views, over the last 12-18 months, of services.

A1 Over the last 12-18 months, in an overall, general sense, how satisfied were you with the services (care and professional) you received?

1 Quite dissatisfied
2 Indifferent or mildly dissatisfied
3 Mostly satisfied
4 Very satisfied

SECTION B: USE OF SPECIFIC LEARNING DISABILITY CARE SERVICES

Here are some questions about the use and helpfulness of various types of care services (e.g. respite care, day centres, parents' group, leisure activities, etc.).

B1 Over the last 12-18 months, what types of local care services have you used in relation to your son/daughter?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

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……………………………………………………………………………………………………

B2 Over the last 12-18 months, did these care services help you to deal more effectively with your problems in relation to your son/daughter?

1 No, they seemed to make things worse
2 No, they really didn't help
3 Yes, they helped somewhat
4 Yes, they helped a great deal

B3 What has generally made contact with these services useful or helpful?

……………………………………………………………………………………………………

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B4 **What has generally made contact with these services useless or unhelpful?**

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SECTION C: CONTACT WITH PROFESSIONALS

Here are some questions about the use and helpfulness of various types of professionals (e.g. GP, social worker, psychologist, speech therapist, etc.).

C1 **Over the last 12-18 months, which particular professionals have you used in relation to your son/daughter?**

....

....

....

....

....

C2 **Over the last 12-18 months, did these professionals help you to deal more effectively with your problems in relation to your son/daughter?**

1 No, they seemed to make things worse
2 No, they really didn't help
3 Yes, they helped somewhat
4 Yes, they helped a great deal

C3 **What generally made professional contact useful or helpful?**

....

....

....

....

....

C4 **What generally made professional contact useless or unhelpful?**

....

....

....

....

....

SECTION D: AREAS OF UNMET NEED

In this section, I am going to explore areas of unmet need in relation to you son/daughter.

D1 Over the last 12-18 months, to what extent have local services and professionals met your needs?

1 None of my needs have been met
2 Only a few of my needs have been met
3 Most of my needs have been met
4 Almost all of my needs have been met

D2 What do you consider to be your special needs as arising from your son/daughter's difficulties?

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....

D3 What improvements or additional services are needed to better meet your own needs?

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SECTION F: OVER TO YOU!

This part of the interview is essentially for you to express your concerns and views about anything you feel is necessary or important but has not been sufficiently or adequately addressed as yet.

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