Caring for adults with learning disabilities:
parents' experiences and the role of respite care

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ABSTRACT

This study had two main aims, to explore parents' experiences of caring for their adult

offspring with learning disabilities and the factors contributing to their experience, as

well as to explore the role of respite care in the parental caring experience. Parents

using three different respite care services were approached, with the researcher visiting

62 parents of adults with learning disabilities in their homes. Structured interviews

encompassing mainly quantitative measures, were carried out with the participants.

Overall, participants in this study were not functioning as well as other caregivers and

the general population. There was variation in parents' caregiving experiences with the

majority reporting some stresses in their caregiving role, and a minority reporting no

stress. There was also variation in parents' experiences over time, with some parents

finding their caregiving role harder over time and others reporting that it was easier.

Various factors were found to be associated with the positive and negative outcomes

of parental well being. Overall parents were satisfied with respite care services,

although there was no association between respite care use and parental well being.

Parents did however feel that respite care was beneficial, predominantly in enabling

them to have a break from the caregiving role. Finally, the salience that parents place

on their post parental life style, whether they were captive or captivated parents, was

significantly associated with some aspects of parental well being. The findings are

discussed in the light of general psychological frameworks, and the implications are

considered for participants, researchers, clinicians and other professionals.

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Chapter One

INTRODUCTION

Overview and background to the study

Family care is and always has been the dominant residential arrangement for people

with learning disabilities (Seltzer, 1992), with the vast majority of people with learning

disabilities living with their families (Fujiura, Garza & Braddock, 1989). Although the

probability of people with learning disabilities living with their families decreases with

age, out-of home placement is not the predominant residential arrangement until

parental death or disability occurs (Meyers, Borthwick & Eyman, 1985). Government

policy initiatives and public resources have however, been directed primarily toward

those who live away from their family home. This has consequently placed less

emphasis on family-based care.

Until recently, the main research focus in learning disabilities family-based care has

been on young children with learning disabilities and their families (Blacher, 1984;

Byrne & Cunningham, 1985). This has left many questions unanswered. What

happens when the child grows up to become an adult? Does caring become easier or

harder as parents and the disabled person become older? Rising living standards, better

health care and service provision have improved the life span of people with learning

disabilities, with their life expectancy now approximating that of the general population

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(Grant, 1990). It is therefore now common for a person with learning disabilities to outlive his or her parents, perhaps having continued to live at home for several decades after the parents are no longer fully able to provide care (Janicki & Wisniewski, 1985). The extent of the aging population of parents of adults with learning disabilities is illustrated by the results of a recent U.K. study (Prasher, Clarke, Harris & Hunt, 1995). Single carers were reported as having a mean age of 64 years, with 56% over 60 years old, and the primary carer of dual carers, a mean age of 57 years, with 43% over 60 years old.

How do parents experience this 'career in caring' which often extends beyond three or four decades? Although the evidence suggests that increasing numbers of aging parents face their retirement years with the responsibility of caring for dependent adult sons and daughters with severe disabilities, little is known about this emerging group of older caregivers (Greenberg, Seltzer & Greenley, 1993). Their experiences have been somewhat neglected, with increasing attention focused on this group only in recent years (e.g. Greenberg et al.,1993; Seltzer & Krauss, 1989).

Parents' experiences of caring have an increased significance when the documented withdrawal of formal support services for adults with learning disabilities is considered (Suezle & Keenan, 1981). The importance of support as a factor influencing parents' experiences of caring, together with other factors, such as challenging behaviour and physical dependency (Grant & McGrath, 1990), have also been explored in the literature. The identification of these factors is important, to enable learning disability services to recognise families who may be experiencing difficulties in the care of their

adult relative. Appropriate services and/or interventions may then be offered to such families to meet their particular needs.

Considering the large number of adults with learning disabilities living at home, the provision of adequate and satisfactory support services for them and their families is consequently of increased importance. Respite care is one such support service available to parents, traditionally described as providing short, regular breaks to the main carers of an adult or child with learning disabilities (Stalker & Robinson, 1994). Although the concept of respite care is intuitively appealing, the role it has in the care giving experience for parents is important to ascertain.

The aims of this study are consequently two fold: to explore parents' experiences of caring for their adult offspring with learning disabilities, particularly those factors influencing their experience; and secondly to explore the role of respite care in parents' experiences of caring for their offspring.

As much of the research in family-based care has been carried out with learning disabled children and their families, this chapter will begin with a brief review of the literature on the impact on the family of having a child with a learning disability. The variation in care giving across the life span will be explored to illustrate the need to extend the focus of research on the family impact from children with learning disabilities, through to the old age of the parents and the child. The models and theories put forward to explain care giving will be described, before examining the research literature on the experiences of parental carers of adults with learning

disabilities. The factors influencing parents' experiences will then be explored. The next section in this chapter will focus on respite care as a support service to families of adults with learning disabilities. The literature reviewing the effectiveness of respite care and parental satisfaction with respite care services will be explored. The rationale of the present study will then be described before specifying the research questions this study will address.

Parents of children with learning disabilities

As mentioned the main research focus in learning disabilities family-based care has been young children with learning disabilities, and their impact on their families (Blacher, 1984). The studies considering such families however, do not provide a conclusive picture regarding the impact of having a child with disabilities in the family. A number of studies report elevated parental stress for parents of children with a disability, (Bradshaw & Lawton, 1978; Chetwynd, 1985; Dyson, 1996; Dyson & Fewell, 1986; Friedrich & Friedrich, 1981; Fuller & Rankin, 1994), whereas other studies however, detected no differences in parental well-being (e.g. Christenson, 1990; Harris & McHale, 1989, cited in Dyson, 1993).

Dyson (1993) explored parental stress and family functioning at two points in time, four years apart in families with a learning disabled child, and those without a learning disabled child. Parents of learning disabled children experienced much higher levels of stress at both points in time, and over time parents of children with disabilities

experienced increased parental stress relating to two aspects in particular: parent and family problems in the care of the child, and parental pessimism regarding the child's future. Interestingly, however, families of children with disabilities were primarily like families of children without learning disabilities in the stability over time of overall parental stress and family functioning, i.e. there was a high degree of stability in parental stress from early childhood to school years in both groups.

These results were also supported by a study by Carpiniello, Piras, Pariante, Carta and Rudas (1995), where parents of disabled children presented with higher levels of psychiatric symptoms and were more likely to meet the criteria for depressive disorders. They also reported considerably more subjective and objective burden of care than parents of non-disabled children.

Research has also sought to identify risk factors for out of home placement and deleterious parental outcomes in families with children with learning disabilities. Demographic variables such as the number of parents in the home and family income, have been shown to be associated with parental stress, although the data are equivocal. Beckman (1983) concluded that single mothers experience more stress, whereas in samples of older children, Bradshaw and Lawton (1978) and Butler, Gill, Pomeroy and Fewtrell (1978), cited in Byrne and Cunningham (1985),found no difference between one and two parent families. Similarly, Bradshaw and Lawton (1978) reported that family income was related to levels of stress, whereas Butler et al. (1978) found no significant relationship.

Diagnostic group differences have also been demonstrated to be important contributors to the variation in parental and familial well-being in families of young children with various causes of learning disability (Gallagher, Beckman & Cross, 1983). Existing research reveals families of young children with Down's syndrome differ from families whose child's disability is due to other factors (e.g. autism). Mothers of children with Down's syndrome report more cohesive and less conflicted family environments (Mink, Nihira, & Meyers, 1983, cited in Seltzer, Krauss & Tsunematsu, 1993); they have larger and more satisfying support networks (Erickson & Upshur, 1989; Goldberg, Marcovitch, MacGregor & Lojkasek 1986, cited in Seltzer et al. 1993); and lower levels of parenting stress (Goldberg et al., 1986).

Research also suggests that other characteristics of the child with learning disabilities are associated with parental stress, notably behaviour problems (Chetwynd,1985; Quine & Pahl, 1985) and the physical dependency of the learning disabled child (Tew & Lawrence, 1975).

Other researchers have identified resources and supports that families utilise to buffer the stress associated with care giving. These include strong and satisfying parental social support networks (Tausig, 1985), the quality and strength of the parental relationship with the child (Blacher, 1984), and effective parental personal coping skills (Friedrich, Wilturner & Cohen, 1985). Positive effects of informal and formal support resources on the well being of family members have also been reported in other studies, (Dunst, Trivette & Cross, 1986; Orr, Cameron & Day, 1991, cited in Heller & Factor, 1993). This is further illustrated by Chetwynd's (1985) findings that mothers of

learning disabled children who had a restricted social life, and those who had not had a break away from their children were found to experience higher levels of stress. Informal and formal support resources are also reported as reducing the out of home placement of children with mental retardation (German & Maisto, 1982; Sherman, 1988; Sherman & Cocozza, 1984). Two studies have however, found that formal support was a non significant (Cole & Meyer, 1989) or only moderate (Bromley & Blacher, 1991) predictor of parents plans to seek placement in the future.

Positive impacts associated with parenting a child with learning disabilities have also been noted, with many parents attributing increased family cohesion, newly developed coping skills, and enhanced personal faith to the challenge of parenting a child with learning disabilities (Abbott & Meredith, 1986; Noh, Dumas, Wolf & Fisman, 1989 cited in Seltzer & Ryff, 1994).

Summary

Although some studies suggest parents of learning disabled children do not experience any deleterious well-being, the majority of research studies suggest that mothers of children with learning disabilities do experience high levels of stress. As Wikler (1981) concludes: 'Families with a child who is mentally retarded are more likely to experience stress, all things being equal, than families who have normal children' (p.281).

Research also suggests a number of factors may influence the experience of parenting a

child with learning disabilities. These include the demographic variables of the parents and the child (notably the diagnosis of the child), levels of challenging behaviour and the physical dependency of the child, as well as the levels of formal and informal support available to parents.

However, it should be acknowledged that overall adaptation in families with a child with learning disabilities is quite varied, with some positive impacts noted. Some families cope well, whilst others manifest more serious problems. Therefore a more cautious conclusion is that family care giving for a child with learning disabilities has both stressful and gratifying aspects (Bristol & Schopler, 1984).

Care giving across the life span

The previous section briefly reviewed some of the research literature on the impact on families of having a child with a learning disability. The extent however to which these findings generalise to families at a later stage of life is unknown. This section of the chapter illustrates the variations in care giving that can occur across the lifespan when parenting a person with learning disabilities, and consequently highlights the potential invalidity of generalising findings from families of children to families of adults with learning disabilities.

Periodic stresses

The early literature on familial responses to learning disability suggested that adapting

and accepting a child with learning disabilities was time limited with parents passing

through a number of stages. Blacher (1984) described these stages of parental

adjustment as: (i) initial crisis responses (shock, denial, and disbelief), (ii) emotional

disorganisation (guilt, disappointment, anger, and lowered self-esteem), and finally (iii)

emotional reorganisation (adjustment and acceptance).

Since then some writers have however suggested that coming to terms with the

meaning of and implications of their offspring's disability cannot be confined to the

early years of parenting, since the experience of care giving is not uniform across the

life span. Over the life course, parents encounter a number of novel situations and

problems that require new coping strategies to be found (Wikler, 1981).

Wikler (1981) suggests parental awareness of the stresses involved in caring for a

learning disabled family member increase periodically. Such increases occur as a result

of parental heightened sensitivity to the failure of their son/daughter to conform to the

cultural norms of family development i.e. "when a discrepancy emerges between what

parents expect of a child's development and of parenting as opposed to what actually

takes place when bringing up a child with learning disabilities" (Pp 283-284).

An example of such a discrepancy is starting work, where the learning disabled

individual may be attending a day centre, rather than working for an employer. Wikler

(1981) suggests that these discrepancies lead to the precipitation of crises which

result in the family experiencing renewed emotional upheaval; they are periodic

awakenings of the 'chronic sorrow' of having a child with a disability (Wikler, Waslow

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& Hatfield, 1981). Following such crises, families then have to reactivate their coping

mechanisms to re-establish family functioning. Consequently care giving is said to be

the most stressful at expected times of family and social transitions, such as when the

child completes school, and it is least stressful during periods of continuity and stability

in family roles (Wikler, 1986).

Thus, although becoming a parent of a child with learning disabilities is a form of

'identity transformation' (Strauss, 1959, cited in Todd & Shearn, 1996a), it is likely

that it involves a series of changes, or of 'coming to new terms', as parents chart the

direction of their lives over a life time.

<u>The family life cycle</u>

An additional source of life-span variation is the extent to which parenting a dependent

son/daughter is a normative versus an 'off-cycle' parental role. Birenbaum (1971)

noted that families with learning disabled children may experience an 'arrest' in the

family life cycle, as they are out of synchrony with their age peers whose children

develop normally. This 'arrest' persists into adulthood with families being 'off cycle'

due to the prolonged and special nature of the dependency of the learning disabled

person. This in turn may affect the personal and social well being of the caregivers.

One particular family life cycle stage, the 'empty nest' transition is more likely to be

unavailable to parents of adults with learning disabilities, than to other parents

(Deutscher, 1962, cited in Todd, Shearn, Beyer & Felce,1993). Post parenthood is

seen as the stage in the family life cycle that is associated with heightened well-being

and life satisfaction stemming from the liberation of day to day family responsibilities

(Glenn, 1975, cited in Todd et al. 1993). Harkins (1978), cited in Todd et al. (1993),

reported that being off cycle in terms of this transition can have negative effects upon

parental well being. Parents of 'normal' children must change their role of caregiver as

the child matures and becomes independent, but in the case of offspring with learning

disabilities, although the parents may experience change in some social roles, the

parent's role as caregiver continues throughout the years. Thus, they find themselves

unable to change or alter their parental role and may see their offspring with disability

as responsible for their lack of access to the opportunities discovered by their peers in

their postparenting stage of life.

Issues particular to parental carers of adults with learning disabilities

The experience of parenting offspring with learning disabilities can therefore vary

across the life span dependent on whether the individual with learning disabilities is in a

'normative or non-normative' role , and similarly whether the parenting role is

normative for parents at their stage in the family life cycle. In addition to this, there

are other issues particular to parents of adults with learning disabilities which may

affect their experience of caring.

These parents face the challenge of adjusting to their own aging as well as continuing

to care for their adult child, leading to the "two-generation elderly family" (Janicki,

1992). Parents may find themselves sandwiched between the needs of two generations,

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a phenomenon known as 'women in the middle' (Brody, 1990), as their parents or spouses become frail and require care in addition to the care they provide to their adult child with disabilities. Whereas caring for a frail elder is becoming an increasingly normative life role (Brody, 1985), caring for an adult child with a disability is not, as it is off cycle and extremely long in duration (Cohler, Pickett & Cook, 1991). The length of caring for an adult son or daughter with disabilities can span five or six decades, whereas care of an elderly relative tends to be relatively brief - about five years on the average (Stone, Cafferata & Sangl, 1987).

In addition to issues related to the length of care giving, and other possible care giving roles, parents of adults with learning disabilities have been shown to receive less support, and to be in greater need of services than parents of children with learning disabilities. For example, parents of adults (up to 21 years old), were less supported, more isolated and more in need of expanded services than parents of children (Suezle & Keenan, 1981). Todd, Shearn, Beyer and Felce (1993) found that service support was less available to families of older than younger adults and that additionally, the level of service planning for individuals aged 25 and over was severely deficient. This decline in the professional services available to parents of adults with learning disabilities was also noted by McGrath & Grant (1993) in their cross sectional study of 190 families at different stages of their life cycle. Carers of adults were reported as lacking the necessary expert help and as a result were noted as being particularly vulnerable as a group of caregivers. McGrath & Grant (1993) also reported that the support network of parents decreased as the age of the adult with learning disabilities increased. This decrease in support network size, was essentially due to ill health and

death. This is occurring at a time when the increasing frailty of carers may mean that they require more help, particularly with the physical care of their dependent.

The following quote from Glendinning (1983, cited in Bose, 1989), suggests what parents experiences may be like,

"...the day to day care needed by a severely disabled child in many respects represents a prolonging of the dependence of early childhood long past the ages at which they otherwise cease. Thus the bathing, feeding, toiletting, lifting and carrying, continuous attention and supervision, disturbed sleep and restricted social life which are common features of looking after an infant can persist for many years and, indeed, can become increasingly difficult as the child gets heavier and the parents grow older"   (p. 41)

From a child to an adult with learning disabilities

The information presented on the variation in care giving across the life span, as well as those issues which are particularly pertinent to parents of adults with learning disabilities, suggest that generalising the research findings from families of children to families of adults may be unwarranted. The changes that occur over the life span suggests that the patterns of individual and family adaptation observed during the first decade of a child's life may not be characteristic of how the child functions when s/he is an adult, in his or her 30s or 40s, and the parents are in their 60s or 70s.

Considering the large population of parents caring for their adult offspring with

learning disabilities, the dearth of information available on their experiences and the uniqueness of their role, there appears to be an important need to extend the focus of research on the family impact of a child with learning disabilities through to the adulthood and old age of both the parents and their son/daughter. Such information would be invaluable for service providers and professionals working with this group and their families in the provision of appropriate and satisfactory services.

Theories and models of carer wellbeing

In order to provide an understanding of the complex nature of care giving, a number of theories and models have been put forward within the research literature. These will be explored within this section of the chapter.

Theories of carer well being

Two competing hypotheses have been advanced in the literature to account for the impact of care giving (Townsend, Noelker, Deimling & Bass, 1989). The first is the 'wear and tear hypothesis'. This predicts that over time family care giving will have a negative effect on the caregiver's physical and mental health, more than on others their age (Seltzer & Krauss, 1984; Hoyert & Seltzer, 1992). The longer the period of family care giving, the more negative the outcomes for the caregiver, as a result of cumulative stress. The other hypothesis is the 'adaptational hypothesis' which predicts that new adaptive capacities emerge during the course of care giving. This suggests that stressful events and roles can be opportunities for personal and psychological growth.

According to this hypothesis, care giving is perceived as being most stressful when it is a new role, but over time it provides an opportunity for development of new coping strategies and manifests psychological growth. It is possible therefore that the longer the duration of care, the greater the potential for adaptational processes to be manifested.

Research in other areas of care giving provides support for both of these theories. Studies looking at the impact of care giving on caregivers of the impaired elderly suggest that long term care giving results in considerable personal stress and burden for the caregiver (Cantor, 1983; George & Gwyther, 1986; Zarit, Reever, & Bach-Peterson, 1980, all cited in Seltzer & Krauss, 1994). This provides some support for the wear and tear hypothesis: the longer care is provided, the more psychological strain caregivers experience. However, Townsend et al. (1989) found that many adult children who provided interhousehold care to an impaired elderly parent showed stability or improvements in their psychological adaptation over time, rather than deterioration. In addition they also reported that the duration of the care giving was unrelated to the caregiver's psychological well being, thereby providing preliminary support to the adaptational hypothesis. Other longitudinal studies have also found that adaptational processes develop in caregivers in response to prolonged periods of care giving. For example, Zarit, Todd and Zarit (1986), reported that some caregivers improve their ability to cope with the problem behaviours manifested by the care recipient, even though such behaviours become more extreme over time.

Models of carer well being

Various models of carer well being have been proposed in the research literature. One such model is that put forward by Pearlin, Mullan, Semple and Skaff, (1990). This consists of three broad domains: (1) sources of stress, the stress-inducing events or circumstances that give rise to stress; (2) moderators of stress, which may be exacerbating or regulating in their influence on the stress process, and (3) the manifestations of stress, including perceived stress as well as a variety of psychological and physical indications of stress. In this model the relationship between stress and well-being may be moderated by a variety of social resources e.g. formal, social or family support. While this model has tended to focus on negative outcomes, there is emerging recognition that the care giving experience consists of positive as well as negative outcomes (Pruchno, 1990). These positive effects are derived from family members coping competently with the care giving role and have largely been neglected in carer well being research (Hoyert & Seltzer, 1992). As Crnic, Friedrich & Greenberg (1983) suggest, "a truly comprehensive model (of care giving) must encompass the range of possible positive and negative adaptations as well as the factors that serve as determinants of adaptation." (p. 126)

A further model of care giving has been suggested by Lawton, Moss, Kleban, Glicksman, and Rovine (1991), cited in Smith, (1996), based on research carried out on spouse and adult-child caregivers of persons with Alzheimers disease. This model, based both on Lazarus's theory of coping with stressful events (Lazarus & Folkman, 1984), and a two factor (i.e. positive and negative) view of psychological well being

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(Bradburn, 1969), reflects the belief that care giving is an activity of mixed valence for the caregiver. This model incorporates the positive as well as the negative care giving outcomes, with separate antecedents postulated for the positive and the negative outcomes. There is also an explicit distinction made between the objective and the subjective stressors of care giving, with care giving appraisals being regarded as both an outcome of care giving and as the central mediator between the stressor and psychological well being. Smith (1996) tested this two factor model of caregiver psychological well being with 225 older mothers caring for their learning disabled adult offspring. As expected, greater subjective burden among this sample increased the negative dimension of well being, while greater care giving satisfaction increased the positive dimension. Of particular note, higher levels of positive psychological well being appeared to diminish the subjective burden of mothers, suggesting that aspects of psychological well being may in turn influence how family caregivers appraise the circumstances surrounding their role. This finding emphasises the importance of the positive outcomes of care giving in influencing the care giving experience.

Summary

Two hypotheses of carer well being have been put forward in the literature, the 'adaptational' hypothesis and the 'wear and tear' hypothesis, both of which have some support from general family care giving research. Within the models of care giving examined, there has been increasing recent recognition of the positive outcomes of caring for caregivers. Such models are moving away (as advocated by Byrne & Cunningham, 1985) from the 'pathological' approach to care giving where

psychological impairment is seen as an inevitable consequence of care giving for family members.

Parents of adults with learning disabilities who live at home

Although historically, the experiences of parents of adults with learning disabilities has been a neglected research area, a number of recent studies, both quantitative and qualitative, have been carried out among this group of caregivers. These will be reviewed within this section, followed by a examination of the factors suggested within the research literature to affect the parental experience.

Review of the quantitative research.

The focus in quantitative research has been on the wellbeing of parents of adults with learning disabilities in comparison to other care giving adults and to adults generally, with an emphasis on whether the 'adaptational' or the 'wear and tear hypothesis' best describes their care giving experience.

Seltzer and Krauss (1989) explored four dimensions of maternal well being (physical health; life satisfaction; burden and parenting stress) among 203 mothers of adults with learning disabilities living at home. Mothers in this sample on average compared favourably with other samples of women of their age and samples of other caregivers. Despite the long duration of their caretaking roles, and the unique qualities of their children, many of the mothers appeared to be resilient, optimistic and able to function

well in multiple roles. Mothers had above average health for their age, with a relatively favourable life satisfaction, and about average levels of perceived burden and stress.

Cameron, Orr and Loukas (1991) also examined stress in mothers of adults with learning disabilities whose offspring lived at home, but compared this with those whose offspring lived out of the parental home. The more dependent offspring with behaviour problems who were multiply handicapped and provided the least personal reward to mothers, were most likely to be placed out of home. Those mothers whose children were living at home reported more concerns pertaining to life span care and family disharmony. The authors conclude that the presence of a learning disabled adult in the family home does involve some stress, and that concerns for the future care of their offspring were prominent among these mothers.

By comparing the data from this study with the normative data available on the parental stress measure (measuring stresses associated with looking after learning disabled children), the authors suggest that stress in parents of learning disabled children is higher than that in parents of adults. However, they duly note that this conclusion needs to be viewed with caution, as no information is available on the diagnoses or challenging behaviour of the children used in the normative data. The authors go on to suggest that the results of their study support that of Seltzer and Krauss (1989), that older parents whose adult offspring have learning disabilities do not report as high levels of stress; that parents providing care over long periods of time have adapted to the various stressors experienced, by developing their own coping abilities.

Six dimensions of well being (depression, life satisfaction, burden of care, parenting

stress, physical health, satisfaction with informal support), were explored by Krauss

and Seltzer (1993), among 387 mothers caring for adults with learning disabilities at

home. These dimensions of well being were then compared with selected references

groups (including non care giving older women, caregivers for the elderly and parents

of children with learning disabilities).

In accordance with the literature already examined, the authors found that in general

the mothers in their sample were functioning as well as if not better than the reference

groups. A higher percentage of mothers rated themselves as being in good or excellent

health than both non caring mothers, and other caring mothers. Further more, the

mothers in this sample were equivalent in their mean depression score to a large

sample of non care giving women the same age (Gatz & Hurwicz, 1990), and they

were considerably less depressed than family caregivers for the elderly (Pruchno,

Michaels & Potashnik, 1990; Pruchno & Resch, 1989). With respect to life

satisfaction, the mothers in this sample were more satisfied with their lives than a

sample of caregivers for the elderly (Gallagher, Rappaport, Benedict, Lovett, Silven, &

Kramer, 1985), but comparable with the general population of older people. Regarding

care giving burden and stress, they found that the aging mothers in the sample, were

very similar to both caregivers for elderly relatives (with respect to burden) and parents

of young children with learning disabilities (with respect to parenting stress), even

though their responsibility for are spanned many more decades than those in the

comparison groups (Friedrich, Greenberg & Crnic, 1983; Zarit, Reever & Bach-

Peterson, 1980). Women in this sample were not socially isolated, with social networks

of about the same size as non care givers their age (Antonucci & Akiyama, 1987). In summary, the authors conclude that these findings suggest providing decades of care for a child and then an adult with disability does not have markedly deleterious effects on the physical, psychological, and social well being of older mothers.

In accordance with the increasing emphasis on the positive outcomes of care giving (Pruchno, 1990) and their effects on the care giving experience (Smith, 1996), both the 'frustrations' and the 'gratifications' of later life care giving for mothers of adults with learning disabilities were explored by Greenberg et al. (1993), and compared to those of mothers of adult children with mental illness. Mothers of adults with mental illness reported higher levels of frustrations and lower levels of gratifications than mothers of adults with learning disabilities. The authors hypothesised that this would be the case due to differences in the care giving experience of the two groups, namely the frequent late onset of mental illness (hence giving parents less time to adapt to their offsprings situation), and the often unstable course of mental illness. Although all parents reported feeling burdened by their care giving responsibilities, they also derived gratification in their relationship with their adult child, emphasising the importance of measuring the positive properties of family interaction.

Implications of the quantitative research.

The studies examined in the literature review, suggest that parents of adults with learning disabilities were functioning as well as if not better than other people of their own age, and other caregivers. This would appear to provide some preliminary support

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for the adaptational hypothesis, as described by Townsend et al. (1989) i.e. that over time carers adapt to the demands of their care giving role. However the studies are subject to some methodological limitations, and therefore care must be taken before drawing any conclusions. Firstly the studies are cross-sectional in design and therefore only based on analysis of the later years of the life span. There are no comparisons made between the carers present levels of functioning and the patterns manifested by these families when they were younger. Additionally, due to a lack of information on the comparison data it is not possible to determine whether the differences between the two groups are statistically significant. Finally, only those parents who carried on as caregivers were studied. It is likely that for those whose 'frustrations' outweighed their 'gratifications', then out of home placement would have taken place, leaving a 'positively' biased sample. One drawback to this research focus, that of whether parents have adapted to the care giving role or not, is that it does not allow for the possibility of variation in caregivers' experiences, i.e. that some parents 'adapt' to their role and others suffer 'wear and tear'.

The more recent research reviewed also emphasises the importance of measuring the 'gratifications' of care giving for parents of adults with learning disabilities; highlighting that care giving has both positive and negative outcomes for caregivers.

Overview of qualitative research

The qualitative literature on the accommodation of families to intensive care giving reveals the very many ways in which having a family member with a disability affects

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the tempo of every day life and engenders fundamental changes in the quality of life of caregivers and of families (Todd & Shearn, 1996a; 1996b; 1996c).

One of the most prominent themes that has evolved from the qualitative literature is the importance of and the struggle that parents of adults with learning disabilities have with 'time'(Todd & Shearn 1996a). All parents reported that, 'time was a major preoccupation' p.387), and that being a parent of an adult with learning disabilities meant constant juggling of their resources to the dictates of 'clock time' (p.387), with clockwatching being a common past time. Freed time was available to parents as a result of use of services, but this 'freed time' seldom met the needs of parents, either in terms of quantity or quality. However while services were valued for the time they did create, the service based regulation of time offered a lack of synchronicity with parents' own needs and failed to provide, at least from the perspectives of parents, sufficient time to engage in activities at the same times as their peers.

The qualitative literature also identifies two groups of parents of adults with learning disabilities, described as 'captive and captivated parents' (Todd & Shearn, 1996a; 1996b; 1996c). These two groups of parents are described as 'differing in the salience they attach to the type of liberated lifestyles enjoyed by their peers' (p. 52, Todd & Shearn, 1996c). 'Captive parents' experienced the tasks of parenting as restricting and as ones they would have liked to give up; they desired the lifestyles enjoyed by their peers whose children had left home. Their difficulties lay in the fact that they had invested in an alternative life style that was becoming less and less realisable. Phrases such as ' being a prisoner', 'of not being free', and the yearning for 'Freedom!'

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scattered accounts of their situation. Over time they had realised that a normal life, a symbol of some value to them, was increasingly beyond their scope. Such parents made frequent use of respite care, as it enabled them to emulate a form of post parenthood. They saw this as a form of parole which highlighted rather than diminished their sense of entrapment. Although respite care use allowed them to hold onto a commitment to an alternative lifestyle, the time gained could never be fully satisfying.

'Captivated parents' however, had relinquished their personal aims and had found enhanced positive meaning in their parental role; they held fewer ambitions to have lifestyles that were more like their peers. These parents were aware that without their parenting role they had few other, or no other, roles in which they could invest themselves and their time; loss of the parental role would not only deprive them of a major source of self meaning, but also one that would be difficult to replace. This group also includes those parents for whom the parental identity had always been so important that they had never attached value to maintaining a substantial self outside of the family. For all captivated parents their commitment to the parental role was exposed by their reactions to the experience of respite care...where 'freed time' is experienced as 'waiting'.

The distinction of two groups of parents of adults with learning disabilities suggests that there is a variation in parents' experiences of caring for their adult offspring with learning disabilities, and that one such source of variation is the importance of a postparental lifestyle for parents .

Factors influencing parental experience

The theoretical models put forward to explore caregiver well being suggest that a

number of factors influence caregivers' experiences. These factors, identifying the

likelihood of the 'frustrations' and the 'gratifications' of care giving, will be examined

within this section.

Research suggests that a number of demographic variables of both the parents and the

adult with learning disabilities are important in determining parents experiences.

Seltzer and Krauss (1989) identified a number of factors. Maternal characteristics (age,

level of education, marital status, and income) were strongly related to maternal well

being (physical health and life satisfaction), whilst characteristics of the adult with

learning disabilities (diagnosis, level of retardation and physical health), were

associated with higher levels of parenting stress and feelings of burden in the mother.

Grant and McGrath (1990) also demonstrated that financial difficulties and

demographic variables (age, marital status, gender of person with learning disability)

were important variables in parents expressed needs for a minding service from

services.

Diagnostic group differences have been demonstrated to be important contributors to

the variation in parental and familial well-being in families of young children with

various causes of learning disability. This would also appear to be the case for mothers

with adult sons/daughters notably with Down's syndrome. Lower levels of burden and

parental stress were found for mothers whose adult sons/daughters had Down's

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syndrome than for mothers whose adult offsprings' learning disability was due to other factors e.g. autism (Seltzer & Krauss, 1989). This finding was repeated by Seltzer, Krauss and Tsunematsu (1993). They also found that mothers of adults with Down's syndrome reported less family conflict, higher levels of satisfaction with their informal support networks, and more favourably assessed the adequacy of their adult son/daughter's service (i.e. they perceived that son/daughter had fewer unmet service needs). Holmes and Carr (1991) also found diagnostic group differences when comparing the pattern of care between families of adults with autism, and those of adults with Down syndrome. Overall, parents of adults with autism found caring for their son/daughter more difficult now that they were older.

It has been hypothesised that the reported differences for parents of adults with Downs syndrome is due to a number of reasons, including immediacy of diagnosis, the greater degree of knowledge available to families of people with Down's syndrome regarding etiology and prognosis, and there tending to be less stigma associated with the diagnosis (Seltzer & Krauss, 1989).

Behaviour problems have also been documented in the literature as a factor influencing parental experiences in caring for offspring with learning disabilities. Greenberg, et al. (1993) found that the strongest predictor of maternal levels of gratification was the level of the adults behaviour problems, with more behaviour problems associated with lower gratifications of caring. Grant and McGrath (1990) also found a strong relationship between challenging behaviour and the need for increased support among 190 parents of people with learning disabilities, suggesting this aspect of care to be

critical. Heller and Factor (1993) reported that challenging behaviour was a strong determinant of increased care giving burden over time. Requests for out of home placement are also affected by high levels of dependent and challenging behaviour (Black, Cohn, Smull & Crites, 1985). The functional level of the adult with learning disabilities has also been suggested by Seltzer & Krauss (1989) as an important factor in influencing parents' experiences.

The role of support, informal and formal, in mediating the well being of parental caregivers has also been debated in the literature. Seltzer and Krauss (1989) found that formal support was not related to caregivers wellbeing, and that informal social support, rather than formal support, was related to perceived care giving burden. This finding was repeated by Smith, Fullmer and Tobin (1994). Roccoforte (1991) however, found that both informal support and degree of unmet formal service needs were associated with family care giving stress. Greenberg et al. (1993) reported a number of aspects of support such as the size of the mother's social network, the family social climate, and the adult's participation in an out of home program, as being related to caregiver frustration.

In summary from the research literature a number of factors appear to be important in determining the experiences of parents of adults with learning disabilities. These include the demographic characteristics of the adult with learning disabilities (such as diagnosis), demographic characteristics of the carer (such as age, financial situation, marital status), the level of challenging behaviour of the adult with learning disabilities, the physical dependence of the adult with learning disabilities, as well as the amount of

and type of support available to parents, both formal and informal.

Summary of research literature on parents' experiences of caring for their adult offspring

The research literature suggests that there is some preliminary support for the 'adaptational hypothesis' of caring for this group of caregivers; that parents have adapted to their care giving role. Caution must however be taken before concluding this due to a number of methodological issues. The importance of the positive outcomes of caring, the 'gratifications' of caring for parents has also been emphasised in more recent research. The possible variation in the care giving experience is highlighted by the importance of the postparental lifestyle for parents and the consequential effect of this on parents' views of their caring role i.e. whether they are identified as 'captive' or 'captivated' parents.

Studies have begun to identify those factors which affect the positive and negative outcomes of the caring experience, guided by theoretical models of caregiver well being. Such information is extremely valuable to enable services to identify those families which may experience difficulties in the care of their adult relative, and to be aware of which interventions and services may be appropriate for families, and when they may be needed.

Respite care

Respite care is one of the services frequently offered to families with the aim of providing support for parents and families. The following section in this chapter will focus on the place of respite care as a support service to families of adults with learning disabilities, before exploring the literature reviewing parental satisfaction with respite care services and the effectiveness of respite care.

<u>Respite care as a support service</u>

Respite services provide short, regular breaks to parents of a child or an adult with disabilities (Stalker & Robinson, 1994). There are a number of different types of such services available, including residential provision, family based respite, day services, residential units dedicated to respite, hospital provision, volunteer or befriending schemes, holiday respite and domiciliary services (Cotterill, Hayes, Sloper & Flynn, 1995). The number of these services catering for adults with learning disabilities however, is small (53), compared the total number (265) of such services available in the U.K. (Orlik, Robinson & Russell, 1991, cited in Stalker & Robinson 1994).

The decline of institutional care has meant that the development of adequate and satisfactory support services for the families of people with learning disabilities has acquired an increased importance. Respite care services are consequently seen as an integral part of community care. Despite the documented high value that parents place on respite care (Grant & McGrath, 1990; Tyndall, 1987), respite care is often reported

as an unmet need by parents (McGrother, Hauck, Bhaumik, Thorp & Taub, 1996). Mitchell (1990) found that most of parents reported that their needs for respite were unmet: 71 % of parents had not used a formal respite care service during the past 12 months, and 90% of main carers expressed the need for more local respite care provision.

In general, the purposes of respite programs are to prevent or delay out-of-home placement of the family member with disabilities and improve the care giving capacity of the family (Halpern, 1985; Krauss, 1986). Todd & Shearn (1996b) describe the role of support services as, 'a significant means of alleviating carer stress, consequently, encouraging ongoing commitment to the carer role and therefore, moderating the need for service based alternatives'(p.41). Although the original role of respite was to provide the parent with a break from the caring role, increasing emphasis has been placed recently on the importance of offering a beneficial experience to the service users themselves, with the importance of meeting users' needs increasingly on the agenda (Cotterill, Hayes, Sloper & Flynn, 1995).

Parental satisfaction with respite care

Despite the rapid emergence of respite care as a major support service to parents, surprisingly little evaluation of this service has been carried out. Previous evaluations of institutionally based care painted a bleak picture . Descriptions such as, 'inadequate', 'of poor quality' and as being 'insensitive to the psychological needs of children and their families' were used (McCormack, 1979; Oswin, 1984; Richardson &

Ritchie, 1989, all cited in Jawed, Krishnan & Oliver, 1992).

Those evaluations which have focused on community based respite care however, are on the whole positive and generally tend to suggest high levels of satisfaction with respite care services. For example, Jawed, Krishnan and Oliver (1992) carried out a postal evaluative questionnaire study of 36 parents of children with learning disabilities who used a residential respite care service (community based health service provision). All the parents were satisfied with the quality of care and accommodation offered and were willing to recommend the service to other parents. One area highlighted by the study as being lacking was the lack of awareness of the psychological needs of parents. Nearly half of all parents did not have the opportunity to discuss their worries and feelings before using the respite service.

Research also suggests differing levels of satisfaction with different types of respite care. Stalker and Robinson (1994) carried out semi structured interviews with 160 parents of children with learning disabilities, using either family based respite, local authority residential homes and health authority provision. Parents who used family based schemes expressed the most satisfaction overall, followed by those who used local authority homes and then finally those who used health authority units. However, even with the latter type of service provision, three quarters of parents reported general satisfaction. Parents using the latter service provision also reported a range of dissatisfactions, mostly associated with the institutional nature of the service. On the whole however parental satisfaction was high.

This as well as other research (Mitchell, 1990) suggests that levels of parental satisfaction are high. Although levels of service satisfaction are important indices of service quality, Shaw (1984), cited in Todd & Shearn (1996a), warns that satisfaction should not be conflated with notions of service effectiveness. He notes, for example, how reported satisfaction may be less a reflection of service efficacy but more indicative of low expectations.

Effectiveness of respite care

Although the concept of respite care for families with disabled members is intuitively appealing, little is known about the effects such care has upon disabled individuals and their families. Despite this, a wide number of possible effects or outcomes have come to be associated with the provision of respite care to this group. Such outcomes include a decrease in the levels of stress experienced by family members, improved family functioning, an increase in positive attitude towards the learning disabled family member, and a decrease in the likelihood of out of home placement (Intagliata, 1986).

Research provides support for some of these outcomes. A number of studies suggest that those families who receive respite services have reduced levels of stress. Rimmerman (1989) for example, compared a sample of 32 Israeli mothers of children with learning disabilities receiving domiciliary respite care, with 25 mothers in a similar but different area, receiving none at four six monthly intervals. An 'immediate significant reduction in maternal stress' (p.99) was found in the former group. This reduction in stress was found to peak after 12 months, with a slight increase in stress

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levels six months later. Bose (1989) compared 48 families who had been using a Link

Family Scheme for a minimum of six months with 18 families on the waiting list for the

service. She found that among the families receiving respite, the main carers

experienced less stress than those who had no breaks. Similarly, Botuck and Winsberg

(1991) evaluated the immediate and short term effects of a preplanned, 10 day

overnight respite on 14 mothers of school age and adult children with multiple

disabilities. Change in maternal mood, well-being, and activity patterns was measured

before, during and after respite. The data indicated that during respite, mothers

experienced increased feelings of wellbeing and less depressed mood. Concomitant

changes in activity patterns were also found. Three to four days after respite, the

increased feelings of well being continued, and there was a strong tendency for

mothers to be less depressed.

Other studies suggest that respite care leads to improved family functioning. Halpern

(1985) compared 31 families who use respite care services with 31 families who do

not use respite care. She found that there was evidence to support the usefulness of

respite care in making a difference in the ability of families with learning disabled

children to recover from stress, by maintaining and strengthening family functioning in

selected areas. Cohen (1982) reported a study where data regarding the effectiveness

of respite care in 357 families were collected over a two year period. The results also

suggest that respite care improves family functioning, with greater improvements in

family functioning significantly related to the greater use of respite care. In addition,

Cohen reports that if respite care had not been available about 25% of families would

probably not have been able to cope with the disabled family member within the home,

and another proportion would have experienced severe stress with the resulting need

of other support services. It is not clear however, how these figures are arrived at.

The value of respite is also supported by the results of Oswin's (1984) British study,

where informal interviews were carried out with 90 parents. She concluded that respite

care may prevent or delay the admission of the child to long term care, and prevent

marital and sibling stress and family break up.

The relationship however between respite care and family stress is complex. One

study found no relationship between the numbers of hours of respite care parents

received and the overall ratings of improvement in quality of life (Joyce, Singer &

Isralowitz, 1983). Few parents cited respite care as enabling them to spend more time

with other family members, promoting better family relationships, or enabling them to

feel less tired from caring for their son or daughter. Rather the knowledge that relief

was available if required enabled parents to cope better. Other research reaches more

cautious conclusions regarding the benefit of respite care. While providing parents with

vital support, it may not be powerful enough to bring about all the benefits sometime

claimed for it (Salisbury, 1986).

Intagliata (1986) in his review of the earlier literature concluded that the available

evidence does not substantiate the claims that respite care alleviates stress in the

primary carer. He analysed the available outcome research on respite care and

concluded that the existing evidence failed to support prevalent assumptions about the

use and impact of respite care and that the results of available studies were weak. He

commented on the design flaws of these studies, such as the use of nonstandardized

measures, scoring procedures which render many studies non-replicable, a lack of

pretreatment (baseline) data, a lack of control groups, and the need for multiple ratings

over time. Some of the latter research (e.g. Rimmerman, 1989; Botuck & Winsberg,

1991) described above, does address some of these methodological issues with

positive results regarding the effects of respite care.

A recent qualitative study, (Todd & Shearn, 1996b) exploring the impact of support

services on the lives of parents of adults with learning disabilities, suggested that they

can *diminish* rather than strengthen parents commitment to the caring role. They

proposed that the impact of support services varies depending on the salience that

parents have attached to the post parental life style, whether parents are 'captive' or

'captivated' parents, as described earlier within the chapter. For 'captive' parents their

preferred lifestyles were perceived as obstructed by the day to day nature and demands

of parenting. They felt that services helped them survive some of the rigours of

parenting but also heightened their awareness of, and preference for a post parental

lifestyle. Respite from parenting refuelled rather than relaxed their commitment to a

role of being a 'retired parent'. For 'captivated parents' however, support services

maintained their commitment to the parental role. For these parents the parental role

was a major and significant source of well being and there was also an absence of other

roles which they wished to invest time in.

Todd and Shearn (1996b) conclude that it is clear that support services introduce time

out from the parental role. Although this time out could have a revitalising effect, it

also introduced a pause in parents lives where they took stock of their situation and assessed the range and adequacy of their commitments and involvements. For some parents these pauses enabled them to reaffirm their commitment to developing a life for themselves beyond the parental role, but since this was unattainable felt their current situation to be a restrictive one. For other parents the experience of extended pauses in their parental role was experienced as waiting, a typically negative experience. While this reaffirmed their commitment to the parental role, it should also be recognised that this was also a function of having relinquished other aspirations.

Summary

Respite care services are seen as providing support to families with learning disabled children and adults, and as reducing out of home placement. Although parental satisfaction with community respite services is very high, data on the effects of respite care for parental caregivers is equivocal. Research suggests that the salience parents attach to the post parental life style (whether they are identified as 'captive' or 'captivated' parents) can affect the impact of respite care; where respite care diminishes captive parents' commitment to the parental role, and strengthens captivated parents' commitment to the role.

Limitations to previous research

The research exploring parents' experiences of caring for their adult offspring with disabilities reviewed within this chapter has some limitations. These are discussed

below.

Although there has been some recognition of the positive outcomes of caregiving in previous research (e.g. Greenberg et al., 1993), the majority of the research is focused on the negative outcomes of care giving, adopting a 'pathological' view of the care giving experience. The importance of the positive outcomes of caring for parents of adults with learning disabilities and the wide spread effects that this can have, has been emphasised in recent research (e.g. Smith, 1996), and warrants further investigation.

The focus of the majority of the quantitative research in examining parents' experiences has been on whether parents 'adapt' or suffer 'wear and tear' from their caring role. Although of value, the sole use of this approach in studies obscures the possible variation in care givers experiences, such as that highlighted by the qualitative research on 'captive and captivated' parents (Todd & Shearn 1996a; 1996b; 1996c). The possibility of variation within the care giving experience for parents is vital to explore to enhance our knowledge and understanding of this group of caregivers.

There are also some methodological limitations to the previous research due to the cross sectional design of studies. The focus is therefore only on the latter years of caregiving for parents, which does not allow for comparisons of parents' experiences over time. This limitation can be overcome by adopting a longitudinal research approach, which has resource and time implications.

With respect to the studies on the role of respite care, the limitations of previous

research are outlined earlier in the chapter (Intagliata, 1986). These suggest that further research examining the effectiveness of respite care should use multiple measures of carer well being taken at multiple points in time to strengthen research design.

Finally, the majority of research on parents of adults with learning disabilities, has been carried out in America, based on the effects of their government policies and service philosophies, with limited research carried out in Britain. There may be differences between the groups of caregivers on the basis of the effects of such service and government policies, indicating the need for further research in Britain.

Aims of present study

This study has two main objectives, to explore parents' experiences of caring for their adult offspring with disabilities and the factors contributing to their experience; as well as to explore the role of respite care in the parental caring experience. The study has four specific aims:

The first is to explore parents' experiences of caring for their adult offspring with learning disabilities at home. This will be done in a number of ways. Firstly the well being of the parental carer will be compared with selected reference groups along five dimensions of well being (parenting stress, anxiety, depression, psychological well being and the positive affect between parents and their learning disabled offspring), as in the manner of the quantitative research described earlier within the chapter (e.g.

Seltzer & Krauss, 1989; Krauss & Seltzer, 1993). A particular focus will be on the

positive outcomes of caring for parents, as drawn upon by the psychological well being

and positive affect measures. As with the previous research, one aspect that will be

explored is whether the 'adaptational' or the 'wear and tear' hypothesis (Townsend et

al., 1989) is most applicable to parents in this study. The cross sectional design of the

study means that the limitations of the previous research will also apply here, and the

lack of information on the comparison samples means that it will not possible to

determine whether any differences found are statistically significant. Qualitative data

obtained from open ended questions, will be used to illustrate the quantitative data and

to explore parents' current experiences as well as provide further information on their

experiences over time, when their offspring were younger. The use of qualitative

methodology will allow some exploration of any variation among parents' experiences.

The second aim of the study is to explore the factors associated with the 'frustrations'

and the 'gratifications' of caring for this group. The model of caregiver well being used

in this study is based on that put forward by Pearlin, Mullan, Semple and Skaff (1990),

consisting of three broad domains: sources of stress, moderators of stress, and

manifestations of stress. In accordance with the importance of the positive outcomes of

caring (Pruchno, 1990; Smith, 1996), the model focuses on both the positive and the

negative care giving outcomes (see Figure 1). The factors to be measured are those

that have been taken from the research literature and include: demographic

characteristics of the mother, demographic characteristics of the adult with learning

disabilities, the level of challenging behaviour and physical dependence of the adult

with learning disabilities, and levels of formal, informal and emotional support available

to parents.

The third aim is to investigate how satisfied parents are with respite care and to explore the role of respite care in parents' care giving experiences. Parental satisfaction with respite care will be examined. Respite care use (in terms of the amount, frequency, length and recency of use) will be related to the measures of parental well being, to examine whether respite care use is associated with parental well being. Again, this aspect of the study will be subject to the constraints of a cross sectional design, which gives rise to the methodological weakness of a lack of ratings over time (Intagliata, 1986). Parents will then be asked what they see as the benefits of respite care.

The fourth aim is exploratory, and aspires to investigate whether the salience that parents place on their post parental lifestyle (whether they are 'captive or captivated' parents, Todd & Shearn, 1996a; 1996b; 1996c) is associated with their well being. From the literature it could be hypothesised that 'captive' parents will score higher on the negative measures of well being, and 'captivated' parents will score higher on the positive measures of well being.

<u>Research questions</u>

The research questions are as follows:

1) To explore parents' experiences of caring for their adult offspring with learning disabilities.

2) What are the factors associated with the positive and the negative outcomes of care giving for parents ?

3) With respect to respite care:

- are parents satisfied with the respite care they receive?

- is respite care use (amount, frequency, length and recency of use) associated with parents' well being?

- what do parents see as the benefits of respite care?

4) Is the salience that parents place on the post parental life style (whether parents are 'captive' or 'captivated') related to their well being ?

Figure1.Model of caregiver well being (adapted from Pearl et al., 1990)

SOURCES OF STRESS   **MODERATING VARIABLES**   **MANIFESTATIONS OF STRESS**

Characteristics of adult:
-age
-gender   Negatives outcomes ('frustrations' of care giving):
-health   Parenting stress
-diagnosis   Formal support   Anxiety
-challenging behaviour   Depression
-physical dependency

                                    Satisfaction with informal support

                                    Emotional support
Characteristics of parental caregiver:
-age
-care shared?
-health   Positive outcomes ('gratifications' of care giving):
-main carer for other siblings   Psychological well being
-employment status   Positive affect between parental carer and adult
-financial worries

Chapter Two

METHOD

Overview

A survey of 62 parents caring for their adult son/daughter with learning disabilities at home was carried out. Parents were sent questionnaires focusing on the experience of caring for their offspring. The researcher then visited the parents at home and structured interviews focusing on the experience of caring, as well as parental satisfaction with and views on respite care, were carried out. The interviews encompassed mainly quantitative measures.

Participants

Participants were parents of adults with learning disabilities who use respite care services in the London Boroughs of Lewisham and Southwark. The managers of three respite care services in these boroughs were approached with details of the study, and their agreement was obtained to contact the parents of users of their service. Two of the respite care services were residential services, one run by social services and the other by a charity. The third respite service was a social service run family based respite care service, where families in the borough offer respite care to adults with learning disabilities. For the two residential respite services, there was also an

evaluative component to the study, where the services wished to know what parents thought of the service.

A pilot study of three parents of adults with learning disabilities was carried out prior to contacting participants. This was done to assess feasibility of the study as well as the content of the interview schedule.

A letter was sent to all parents of users of the respite care services (all users were aged 18 or over), outlining the study and inviting them to take part (see Appendix 1). This letter was then followed up by a telephone call where the identity of the primary caregiver in the household was established, and further details about the study were explained. If the primary caregiver was willing to take part, an interview time was arranged for the researcher to visit the caregiver at their home. A letter was then sent to participants confirming the interview time and re-iterating the aims of the study (Appendix 2).

Of the 82 parents sent an initial letter, four (4.9%) could not be contacted, 15 (18.3%) declined to take part in the study for a variety of reasons (e.g. health concerns), one agreed to be interviewed but then cancelled on receipt of further information about the study and the questionnaires. The remaining 62 (75.6%) parents took part in the study.

Of the 62 participants, 58 were female and four male. Ages ranged from 37 to 86 years old (s.d. 10.3), with an average age of 60 years. Just over half of the parents were married (n=34, 54.8 %), with 12 (19.4%) widowed, nine (14.5%) separated, five (8.1

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%) divorced, and two (3.2%) single. 36 parents (58.1 %) felt that their care was shared with another person. With respect to their health, 13 (20.8%) rated themselves as being in excellent health, with 25 (40.3%) in good health, 18 (28.8%) in fair health and six (9.7%) in poor health. Twenty two (35.5%) parents had other children living at home. Forty three parents (69.3%) were not in employment, with 17 (27.4%) of those retired. Of those in employment, five worked full time, 12 part time and two voluntarily part time. Of those carers who had partners, 15 (24.2%) of the partners had retired, and 12 (19.4%) were working, with the majority working full time. The majority of parents described not experiencing financial difficulties (n=44, 71.0%).

Of the adults with learning disabilities 28 were female and the remaining 34 male. Their ages ranged from 18 years to 52 years, with an average of 32 years (s.d. 8.9). Half of the adults with learning disabilities (n=31) were rated as being in excellent health by their parent, 23 (37.1 %) as being in good health, six (9.7 %) in fair health, and two (3.2%) in poor health. The majority of adults with learning disabilities were described by their parent as being White British (n=44, 71%), with six (9.7%) described as Black British. Other ethnic groups included Afro-Caribbean (n=4, 6.5%), Asian (n=3, 4.8%), Irish (n=1,1.6%), European (n=2, 3.2%), Portuguese (n=1,1.6%) and British Chinese (n=1,1.6%). Just under half of the diagnoses of adults with learning disabilities were unknown (n=26, 41.9%). Of those that were known, 10 (16.1%) were autism, eight (12.9%) were Downs syndrome and five (8.1%) cerebral palsy. The remaining diagnoses were Retts syndrome (n=3,3.4%), brain damage at birth (n=4,6.5%), hydrocephalus (n=2, 3.2%), meningitis (n=1, 1.6%), Turners syndrome (n=1, 1.6%), phenylketonuria(n=1, 1.6%) and hole in the heart (n=1,1.6%). The majority of adults

with learning disabilities did not have epilepsy (n=51, 82.2%).

Ethical Considerations

Ethical approval for the project was obtained from the Lewisham Hospital NHS Trust Research Ethics Committee (see Appendix 3 for letter of approval).

The letters sent to parents inviting them to take part and confirming the interview time (Appendices 1 & 2) gave an outline description of the study. These letters stated that the study was independent of any input that families may be receiving from services at the moment, and that taking part or not taking part in the study would not affect any services that they currently receive or would receive in the future. They also stated that all information was confidential and would only be available for the purposes of the study.

Prior to beginning the interview, each parent signed a consent form (Appendix 4), and were told that the results of the research would be available to them in due course if they wished to have them.

Additionally, the names and telephone numbers of a family support worker in each of the boroughs were also available to parents. The family support workers could be contacted by parents if they wanted further information or advice on issues that arose within the interview.

Procedure

The researcher visited the parents at their home. The purpose of the study and confidentiality of the interview and information obtained from it, were re-iterated to parents at the beginning of the interview. Participants were sent three questionnaires prior to the interview (the first three described in the measures section), and asked to look over them. If they felt comfortable about filling them in before the interview then they were asked to do so. If not then the questionnaires were incorporated into the interview schedule. Parents then completed a consent form. The interview lasted approximately one and a half hours, and followed a standard sequence of questions interspersed with written questionnaires. The full interview schedule can be found in Appendix 5.

Measures

The full interview schedule comprised both qualitative and quantitative measures.

Positive Affect Scale (Bengtson & Schrader, 1982). Appendix 6.

This is a ten item scale assessing sentiment, or positive affect, among family members as it is perceived and reported by family members. Five dimensions of positive affect are included: the degree of (1) understanding, (2) fairness, (3) trust, (4) respect, and (5) affection. Two items are asked about each of the five dimensions of positive affect, with the referent changed from "other's feelings" to "your feelings." For example in

the first set, the participant is asked, "How well do you feel your son/daughter

understands you?", and in the next set, he or she is asked, "How well do you feel you

understand your son/daughter ?". Responses range from 1("not well") to 6 ("extremely

well"). Scores on the ten items are summed to provide an index of positive affect,

which ranges from 10 to 60, a higher score indicating a higher level of positive affect.

Examination of the psychometric properties of the scale indicate that the internal

consistency of the scale is high (coefficient alpha = .92), and that the test-retest

reliability for the scale is also good (r = .89) (Bengtson & Schrader, 1982). In addition,

examination of the construct validity of the scale with the Interaction Index (Bengtson,

1973) suggests that this is good (correlations ranging from .60 to .80) (Bengtson &

Schrader, 1982).

Short-form of the Questionnaire on Resources and Stress (QRS-F : Friedrich,

Greenberg & Crnic, 1983). Appendix 7.

This is a 52 item self report questionnaire which measures the impact of a learning

disabled, physically handicapped or chronically ill person on family members. The scale

is composed of four sub-scales: Parent and family problems (20 items); Pessimism (11

items); Child characteristics (15 items); and Physical incapacitation (six items). Each

item is a statement to which participants respond True or False, for example, "I have

given up things I have really wanted to do in order to care for _____" is an item

from the parent and family problems sub-scale. A response of 'True' for this item is

scored as 1, and a response of 'False' is scored as 0. Scores within each subscale are

summed to provide four subscale scores. Scores on all items are summed to provide a

total scale score, which ranges from 0 to 52, a higher score indicating a higher level of

parental stress.

Information available regarding the psychometric properties of the questionnaire

indicate that the internal consistency is high (coefficient alpha ranging from .92 to.95)

(Friedrich et al., 1983; Scott, Sexton, Thompson, & Wood, 1989). The internal

consistency of QRS-F is approximately the same for parents of disabled children

(coefficient alpha = .89) as for parents with non disabled children (coefficient alpha =

.88), suggesting that the measure can be usefully applied in experimental and

comparison groups (Scott et al., 1989). With respect to validity, Friedrich et al. (1983)

describe the correlation between the four sub-scales and other independent measures

(e.g. Beck Depression Inventory) as indicative of good concurrent validity. However,

no figures are quoted to demonstrate this. Scott et al. (1989) suggest that the QRS-F

has good construct validity. This is due to the substantial variance in scale scores

associated with families having children with disabilities, and the little variance in

scores associated with the sex of the parents.

Symptom Checklist -90 Revised (SCL-90-R : Derogatis, 1994). Appendix 8

Two sub-scales of the SCL-90-R, the anxiety and depression sub-scales, were

administered to participants . The SCL-90-R is a 90 item self-report symptom

inventory designed to reflect the psychological symptom patterns of medical,

psychiatric and community respondents.

The sub-scales administered to participants assessed their perceived symptoms of anxiety (10 items) and of depression (13 items). Within the study one depression item, referring to loss of interest or pleasure in sex, was discarded following the pilot study, as respondents felt it was too personal. The depression subscale within this study therefore was composed of 12 items. Participants were asked to indicate "...how much discomfort that problem (i.e. each item) has caused you during the past month including today". Responses were rated on a five point scale of distress (scored from 0 to 4) where responses ranged from "Not at all" to "Extremely". Scores are calculated by summing the values (i.e. 0- 4) for the item responses in each subscale, and then dividing this by the number of items scored within the subscale. The scores range between 0 and 4 for each subscale; a higher score indicating a higher reported level of anxiety or depression.

The SCL-90-R has normative data available on four groups, including adult nonpatients. It is a well established measure with extensive reliability and validity data (Derogatis, 1994).

Scales of Psychological Well-Being (Ryff, 1989). Appendix 9.

Three short form subscales of the Scales of Psychological Well-Being were completed by participants. The Scales of Psychological Well-Being is a structured, theoretically guided, self report scale designed to assess multiple dimensions of psychological well being. It is composed of six sub-scales, each sub-scale made up of 20 items which are divided equally between positively and negatively phrased items.

Three short form subscales were chosen: purpose in life; personal growth and environmental mastery. These subscales were chosen as their definitions seemed the most relevant to participants. (For definitions of the subscales, see Appendix 10). The short form of the subscales, consisting of 14 items, were used for brevity. Participants responded to each item using a six-point format ranging from strongly disagree (1) to strongly agree (6). Responses to negatively scored items are reversed in the final scoring procedures so that high scores indicate high self ratings on the dimensions measured. Scores within each scale range from 14 to 84, and the overall well being score ranges from 42 to 252.

The original 20 item parent scales have good psychometric properties, with reported high internal consistency (coefficient alpha ranging from .86 to .93)(Ryff, 1989). Test-retest reliability over a six week period was also good, ranging from .81 to .88 (Ryff, 1989). The scales were shown to correlate positively with prior measures of positive well functioning (have good convergent validity) and negatively with measures of depression and external control (also have good discriminant validity) (Ryff 1989). The short form sub-scales have extremely high correlations with their parent 20 item scales (.97 to .98) (Ryff, 1989). Internal consistency for the three short form subscales were also high (coefficient alpha = .86 for environmental mastery; .85 for personal growth; .88 for purpose in life) (Ryff, 1989).

Demographic characteristics

In accordance with previous literature, information on a number of demographic

characteristics of both the parental carer and the adult with learning disabilities were

collected. These included:

(i) age of person with learning disabilities;

(ii) age of the parental carer;

(iii) whether the care of the adult with learning disabilities was shared;

(iv) physical health of the parental carer (self rated on a scale of 1 to 4, with 4

indicating better health, as in Seltzer & Krauss, 1989; Krauss & Seltzer, 1993);

(v) physical health of the adult with learning disabilities (rated on a scale of 1 to 4, with

4 indicating better health), as in Seltzer, Krauss & Tsunematsu, 1993;

(vi) whether the parental carer is the main carer for any other siblings;

(vii) whether the parental carer is employed;

(viii) if appropriate, whether the carer's partner is employed;

(ix) whether they experience any financial difficulties;

(x) the ethnic group of the adult with learning disabilities;

(xi) the diagnosis of the adult with learning disabilities.

Degree of Dependency Scale (Evans, Caddell & Woods, 1981). Appendix 11

The Degree of Dependency Scale derived from the Wessex Mental Handicap Register

(Kushlick, Blunden & Cox, 1978), was administered to participants to ascertain the

level of physical dependency of their son/daughter. The Degree of Dependency Scale is

composed of four subscales, measuring continence, mobility, problem behaviours and self help ability. Versions of this measure have been used in a number of recent studies (Grant & McGrath, 1990; McGrath & Grant, 1993; Todd & Shearn, 1996 a; 1996b; 1996c).

The version used in this study was composed of three additive scales: continence (four items), mobility (two items), and self-care (three items). Problem behaviours was not included as this is being measured by a separate scale. Each item within each scale has three response categories scored one, two or three. The more able the adult with learning disabilities, the higher the score. For example one item within the self care scale is 'Feeds him/herself'. The response categories are (1) Not at all; (2) With help; (3) Without help. An overall level of physical dependence is determined by adding the scale totals. Scores range from nine to 27, with higher scores indicating a higher level of ability.

With respect to reliability, the Wessex Mental Handicap Register has been demonstrated to have an inter-rater reliability of .68 (May, Hallett & Crowhurst, 1982). Humphreys, Lowe & Blunden (1983) report however, that interviewing staff or parents as opposed to letting them complete the scale unsupervised increases the reliability of the scale to above 0.70.

The Checklist of Challenging Behaviour is an instrument used to ascertain levels of

challenging behaviour among people with learning disabilities. The instrument is

composed of two checklists. The first checklist (13 items) concerns aggressive

behaviour involving harmful, physical contact with others e.g. kicking people. These

behaviours are rated for frequency, severity and management difficulty. The second

checklist (20 items) concerns other types of challenging behaviour, which are not

necessarily directed at others e.g. causing a night time disturbance. These behaviours

are rated for frequency and management difficulty only. Five point scales are used to

rate the behaviours for frequency (between 'never' and 'very often'); management

difficulty (between 'no problem' and 'extreme problem'); and where appropriate,

severity (between 'no injury' and 'very serious injury'). Scores for each behaviour are

summed to provide a total challenging behaviour score ranging from 33 to 395, a

higher score indicating a higher level of challenging behaviour. (Sub scale scores for

aggressive behaviours range from 13 to 195; and non aggressive behaviours from 20 to

200).

Harris et al. (1994) quote percentage agreements to demonstrate the inter-rater

reliability of the checklist. Inter-rater reliability was good regarding whether a

behaviour had occurred or not (82% agreement for the first list, and 81 % agreement

for the second list). However, the rater agreement calculated for the frequency,

management difficulty and severity ratings for both lists were much lower. These

varied between 58 % and 71% agreement. This suggests that the list is a reliable

indicator of whether or not a behaviour has occurred but less reliable on the finer

discriminations of frequency, management difficulty and severity. The content validity

of the checklist has been examined with the consensus being that it has high content

validity (Harris et al. 1994).

Support questions. Appendix 13.

Three aspects of 'support' were measured for the study:

i) formal support

This question was adapted from that used in recent studies (e.g. Greenberg et al.,

1993; Krauss & Seltzer, 1993). Parents were asked what kind of formal supports their

son/daughter received (e.g. day centre, employment, voluntary work, evening

activities, and 'other'). The measure of formal support was the total number of

services (out of five) that were used by the adult with learning disabilities.

ii) informal support

Parents were asked whether they had any friends or family they could rely on to

provide them with support. Prompts were given to clarify the kind of support meant,

for example, "come round and sit with your son/daughter when you want to go out;

take your son/daughter out for a period of time". Parents were then asked to rate their

satisfaction with the informal support they received on a four point scale ranging from

one (not at all satisfied), to four (very satisfied), also used in recent studies (e.g.

Krauss & Seltzer, 1993).

iii) emotional support

A three item measure of emotional support, assessing the level of support available to

the participants in their natural environment, was adapted from the self-report version

of the Social Adjustment Scale (Weissman & Bothwell, 1976; see also Zemore &

Shepel, 1989). The three items asked about the opportunity to discuss one's feelings

and concerns with friends, relatives and spouse/partner. (Respondents without a

partner omitted the third question.) Each item was rated on a five point scale, with a

higher score indicating greater support. An overall score for level of emotional support

ranging from nought to five, was obtained by averaging responses across the

completed items.

Open ended questions (Appendix 14)

Participants were asked three open ended questions, to gain qualitative information

regarding their experiences of caring for their son/daughter. The responses were

written down verbatim.

(1)We know that looking after a relative with learning disabilities can be stressful, what

if any, are the stresses for you?

This was asked to illustrate the quantitative data and provide information on parents

current experiences of caring.

(2) Have these stresses changed over time, since *(name)* was a child?

This was asked to provide information on parents experiences over time.

(3) How different do you think your life would be if *(name)* was not living at home?

This was asked to ascertain the importance to parents of the post parental lifestyle and

to determine whether parents were 'captive' or 'captivated' parents, as described by

Todd & Shearn (1996a; 1996b; 1996c).

Respite questionnaire. (Appendix 15).

The questionnaire was constructed to ascertain parents pattern of respite care use,

their satisfaction with respite services and what benefits, if any parents thought respite

care use had for them. The questions are mainly quantitative, all having been used in

previous research.

Pattern of use.

Questions 1 - 4 were taken from Jawed et al.'s (1992) evaluative study of respite care.

They asked about parents last use of respite care, length of use of respite care services,

frequency of respite care use, and total annual use of respite care. These were asked to

determine the use of respite services, and for this to be related to the measures of

parental wellbeing.

Parental satisfaction with respite services.

Question 5 was taken from Stalker & Robinson's (1994) evaluative study on respite

care, and asked whether parents were satisfied with the discussion and planning they

had with staff about their son/daughter's respite stay. Questions 6-8 were three out of

the eight items of the Client Satisfaction Questionnaire, (CSQ : Larsen, Attkisson,

Hargreaves & Nguyen, 1979), designed to assess client satisfaction with health

services. These were asked to determine parental satisfaction with respite services.

Benefits of respite care for parents.

Question 9, an open ended question, asked parents about the benefits if any of using

respite care. It sought to determine how parents perceived they benefitted from respite

care use.

Chapter Three

RESULTS

Overview

This study aims to address four research questions. Within this chapter, the results for each question are presented in turn. The experience of the parental carers is examined first, followed by the factors associated with the positive and negative measures of wellbeing. The research questions addressing respite care, whether parents are satisfied with respite care, whether respite care use is associated with parental wellbeing, and what parents consider to be the benefits of respite care, are then examined. The final research question, whether the salience that parents place upon their post-parental identity is associated with their wellbeing, is then addressed.

Parents of adults with learning disabilities: their experiences of caring

Table 1 presents the means, standard deviations and range of scores for all the measures of parental wellbeing and their respective subscales. Table 2 shows the inter-correlations of the dependent variables. As would be expected, the positive measures of well being (positive affect and psychological well being) are positively related to one another and negatively correlated with the negative measures of well being (parenting stress, anxiety and depression).

Table 1. Parental well being measures.

Measure	Mean score	SD	Range of scores	Norms/results from previous studies (Means)
Positive Affect Scale				
Positive affect between family members	49.61	8.14	25-60	49.99 (Mothers of awld)c
Questionnaire on Resources and Stress				
Parenting stress total	22.48	9.29	8-42	17.6 d; 16.0 e; 18.6 f
Parent and family problems	6.86	4.68	0-17	
Pessimism	7.86	2.20	2-11	
Child characteristics	6.08	3.80	1-15	
Physical incapacitation	1.69	1.73	0- 6	
SCL-Anxietya	0.39	0.51	0-2.6	0.19 - 0.20 (Nonpatient adults)g
SCL-Depressiona	0.69	0.64	0-2.7	0.28 - 0.31 (Nonpatient adults)g
Psychological well being b				
Total score	179.21	23.27	115-213	207.8 (Mothers with adult children)h
Environmental mastery	61.18	9.60	35-78	66.6 (Mothers with adult children)h
Personal growth	58.75	9.05	42-74	72.1 (Mothers with adult children)h
Purpose in life	59.28	9.46	34-81	69.1 (Mothers with adult children)h

Note. N=62, apart from a where n = 58, and b where n = 57. c Greenberg et al. (1993); d Seltzer & Krauss (1989); e Krauss & Seltzer (1993); f Friedrich et al. (1983); g Derogatis (1994); h Ryff, Lee, Essex & Schmutte (1994).

Table 2. Inter-correlations of the parental well being measures

Measure	1	2	3	4	5
1. Positive affect	1.00				
2. Parenting stress	-0.61***	1.00			
3. Anxiety	-0.26*	0.28*	1.00		
4. Depression	-0.32*	0.45***	0.73***	1.00	
5. Psychological well being	0.26*	-0.24	-0.38**	-0.49***	1.00

*p<0.05, **p<0.01,***p<0.001.

Table 1 also presents the means of the parental wellbeing measures with selected

reference groups. This enables the results of this study to be placed in the context of

other studies, and the wellbeing of these parental carers to be considered in relation to

other caregivers and to available normative data.

The positive affect between parents and their offspring in this sample is similar to that

reported in previous studies of parents of adults with learning disabilities (Greenberg et

al., 1993). Parental stress, however, is higher in this study than in previous studies,

compared to both parents of adults (Krauss & Seltzer, 1993; Seltzer & Krauss, 1989),

and parents of children with learning disabilities (Friedrich et al., 1983). The levels of

anxiety and depression reported are slightly higher than in a normative population, with

anxiety in the 70th centile and depression in the 82nd centile (Derogatis, 1994).

Psychological well being is also slightly below that obtained in a previous study of mid

life mothers (mean age 53.1 years) with adult children (Ryff et al., 1994).

In comparison therefore to other samples of carers and to normative data, parents in

this sample have higher levels of parenting stress, higher levels of anxiety and

depression, lower levels of psychological well being and approximately equal levels of

positive affect. There are of course limitations to these comparisons, as it is not

possible to determine the statistical significance of such differences due to a lack of

information about the comparison samples.

The open-ended questions provide further information about parents' experience of

caring. Responses to the question, 'We know that looking after a relative with learning

disabilities can be stressful, what if any are the stresses for you?', fell into one of three categories: stressful, some aspects stressful and not stressful. A second rater, a clinical psychologist in training, independently coded the data and obtained good inter-rater reliability (Cohen's kappa = 0.84).

Stressful

Over half of the responses were coded as stressful (56.5%, n=35), with varying 'stresses' given. Some parents mentioned aspects of their offsprings behaviour, for example: " As she has challenging behaviour, I have to be aware of what she's doing....checking her every 10 minutes. She's fascinated with water. I'm constantly aware of her, watching for changes in her behaviour. It's like that 24 hours a day...I never switch off. I have to stick to a routine...if the routine is broken, she doesn't like it....she needs a constant routine. I have to be careful where I take her if we go out, as she attacks screaming babies". (P10)

Other parents referred to the effect their caring has had on their own lives and their identity: "I always have to be there for him, always have to be back for 4p.m......I wouldn't leave him on his own. You haven't got your own identity. I have to consider him with everything for example, if I want to go out, he has to come or I have to find someone to be with him. I'm not a free agent, I have to consider how decisions I make will affect him. He always has to come first". (P14)

One parent referred to the stresses of dealing with services:

"The authorities put on unnecessary stresses...for example..support workers sometimes think that they know everything. I sometimes feel that I am under a camera all the time, for example if he gets a bruise, I wonder should I let the day centre know...and then they say that they know...he banged his leg there the other day. I sometimes feel that they are waiting to catch me out so that he can go and live in residential services. I feel intimidated by them sometimes...that they know best , better than me...they don't appreciate what I know about him". (P2)

Some aspects stressful

Other parents (24.2%, n=15) reported some aspects of stress in their caring role, due in part to concerns about their offspring's vulnerability: " She's not hard work to look after at all. She sits upstairs doing jigsaw puzzles, watching videos. She mixes with everyone too. The only problem is her vulnerability with strangers. She goes to a day centre with an escort, the day centre don't understand, she doesn't have behavioural problems or anything...but I worry about someone taking advantage of her ". (P35)

Not stressful

Others (19.4 %, n=12), reported that their caring role was not stressful to them: " I don't find it stressful at all. I don't look back, it's a waste of time. I've always had support from my husband and my daughters.....we're a happy family. Where ever we go, she goes too. We've got a pattern now, a way of doing things".(P34)

Further information about how the caring experience has changed over time for parents was gained from the question, "Have these stresses changes over time since

(name) was a child?" The responses fell into four categories: caring harder now, caring

easier now, the same as before, some aspects harder some easier. Two raters

independently coded the data and obtained good inter-rater reliability (Cohen's kappa

= 0.81).

Caring role harder now

Just under half of all parents, (43.5% n=27) of parents felt that their caring role was

harder now. As one parent said: " It's much harder now. It was easier when she was a

child, it was just like managing another child. All the things that make it stressful now

have emerged since she's got older - since she's become an adult".(P58)

Some parents made reference to their age in making the caring role more difficult, as

well as worries about who would care for their offspring when they are unable to:

"Harder...because I'm older now. She's never got better..she may have improved from

the age of 0 to 15, but nothing's really altered since then. Nothing gets easier...it's

worse as I'm getting older. Who will look after her when I can't?...it drives me mad

thinking about it".(P32)

Others referred to the age and size of their offspring as the factors making it more

difficult: "When she was younger the work was easier. She's a woman now, she's

bigger, heavier. I could handle her when she was younger".(P12)

Caring easier now

Approximately one third of parents, (33.9 %, n=21) reported that caring was easier

for them now. Not having other children to look after anymore at home was mentioned by some parents as why things were easier: "Years ago it was more stressful, I had other young children to look after. I feel for my other two children - they never had a mum. I had a lot to do with her....like take her to physio, I was determined not to have a child stuck in a wheelchair".(P7)

Some referred to how their offspring had developed since they were children: " It's easier now. When she was younger she was worse, she used to wave her hands in front of her face, now she only sucks her tongue. She couldn't walk when she was younger.....her brothers and sisters helped her do that - now she's O.K.". (P36)

Other parents felt that things were the same as when their offspring were younger (n=8, 12.9%), and some felt that certain aspects were harder now and others were easier (n=6, 9.7%).

Summary

In summary, the quantitative data suggest that these parents are not functioning as well as other caregivers and the general population. The qualitative data emphasise the variation in parental carers current experiences, with the majority of carers reporting some stresses in their care giving role, but a minority of carers reporting no stress. The qualitative data on parents experiences over time also illustrate variation, with some parents reporting that care giving was easier as their son/daughter had grown up, and others that it was much harder as their son/daughter had got older.

What are the factors associated with the positive and negative outcomes of care giving for parents?

Table 3 presents the means, standard deviations and possible range of scores for the major independent variables: the level of physical dependency and challenging behaviour of the adults with learning disabilities, and the support available to the parental carers. The other independent variables - the demographic characteristic variables of the parental carer and of the adult with learning disabilities - are described in the method section.

Table 3. Physical dependency and challenging behaviour of adults with learning disabilities, and support available to parents.

Measure	Mean score	SD	Range of scores
Physical dependency scale	22.31	5.68	9-27
Continence	10.15	2.97	4-12
Mobility	5.39	1.29	2-6
Self care	6.77	2.04	3-9
Speech ability	2.29	0.80	1-3
Literacy	4.71	1.75	3-9
Challenging behaviour	53.05	28.06	33-395
Aggressive behaviour	20.63	14.89	13-195
Nonaggressive behaviour	32.42	15.05	20-200
Formal support	1.74	0.72	0-5
Satisfaction with informal support	2.97	0.94	1-4
Emotional support	3.67	1.29	1-5

Table 4 presents the inter-correlations of the continuous independent variables.

Table 4. Inter-correlations of the continuous independent variables.

Variable	1	2	3	4	5	6	7	8	9
1.Age of awld	-								
2.Health of awld	0.11	-							
3.Age of parent	0.82***	0.04	-						
4.Health of parent	0.05	0.32*	-0.03	-					
5.Dependency	0.26*	0.22	0.21	-0.05	-				
6.Challenging behaviour	-0.29*	0.02	-0.29*	-0.23	-0.16	-			
7.Formal support	0.09	0.01	0.24	0.00	0.20	-0.18	-		
8.Informal support	0.18	-0.16	0.19	0.22	0.04	-0.39**	0.16	-	
9.Emotional support	0.09	0.20	-0.03	0.19	0.16	-0.06	-0.18	-0.08	-

Note. awld= adult with learning disability. *p<0.05,**p<0.01,***p<0.001.

As would be expected there is a highly significant correlation between the ages of the parental carers and their offspring (see Table 4). Also from Table 4, older adults with learning disabilities were less dependent and showed lower levels of challenging behaviour. These results are concordant with literature suggesting that adults with learning disabilities who are less able and show higher levels of challenging behaviour, are more likely to have been placed out of home (Black et al., 1985). Of note, there is also a moderate correlation between the level of challenging behaviour and the

satisfaction that parents have with their informal support networks, with higher levels

of challenging behaviour associated with lower satisfaction with informal support

networks (see Table 4).

Other preliminary statistical analyses computed on the categorical independent

variables (independent t-tests, chi squared analyses, one way anovas), reveal a number

of relationships between the independent variables. Only those relationships which are

statistically significant are reported below. Older parents are less likely to experience

financial difficulties (t(46)= 3.15, p<0.01). Those parents with a partner are more likely

to feel that the care of their offspring was shared with someone else (chi-sq (1) =30.7,

p<0.001), are more likely to have offspring who are younger (t(60)=2.15, p<0.05), and

who are significantly less physically able (t(54) = 3.11, p<0.01). Financial difficulties

are more likely for parents whose offspring are more physically able (t(60) = 2.61,

p<0.05). Those parents who are employed reported significantly better health (t(43) =

2.26, p<0.05).

The final step in the preliminary exploration of the data, was to examine the univariate

relationships between the independent variables and the dependent variables. Table 5

presents the correlations between the continuous independent variables and the

dependent variables.

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Table 5. Correlations between the continuous independent variables and the parental well being measures.

Measure	Positive affect	Parental stress	Anxiety	Depression	Psychological well being
Age of awld	0.33**	-0.19	0.01	-0.13	-0.08
Health of awld	0.12	-0.09	-0.13	-0.13	0.15
Age of parent	0.19	-0.21	-0.03	-0.14	-0.17
Health of parent	0.21	-0.19	-0.43**	-0.38**	0.34**
Dependency	0.36**	-0.44***	0.05	-0.14	0.06
Challenging behaviour	-0.34**	0.57***	0.41**	0.56***	-0.14
Formal support	0.14	-0.27*	-0.01	-0.07	-0.11
Informal support	0.40**	-0.49***	-0.43**	-0.47***	0.25
Emotional support	-0.03	-0.11	-0.07	-0.20	0.41**

Note. awld = adult with learning disabilities. *p<0.05, **p<0.01, ***p<0.001.

Other statistical analyses computed on the categorical independent variables

(independent t-tests, chi squared analyses, one way anovas), revealed two additional

relationships between the dependent variables and categorical independent variables.

Higher levels of parental psychological well being are associated with other children

living at home (t(54)=2.91, p<0.01). In addition, those parents with a partner are more

likely to report higher levels of parental stress (t(60)=2.28, p<0.05).

In summary, two variables, the level of challenging behaviour of the adult with learning

disabilities and parental satisfaction with informal support, are significantly associated with four of the five parental well being measures. Dependency of the adult with learning disabilities has significant correlations with two of the measures of parental well being, and the remaining support measures (formal and emotional support) show significant associations with one aspect of parental well being. Of the demographic independent variables, health of the parent significantly correlated with three of the measures of parental well being.

Following the preliminary analysis of the data, hierarchical multiple regression analyses were carried out, one for each measure of parental well being. Seven independent variables were entered in to the regression analyses:

i) demographic characteristics of the adult with learning disability (age, gender, health and diagnosis).

ii) demographic characteristics of the parental carer (age, marital status, whether the care was shared, the health of the carer, whether the carer was employed and whether they experienced any financial difficulties). Gender of the carer was excluded from the analyses due to the low number of men in the sample.

iii) the level of challenging behaviour of the adult with learning disabilities

iv) the level of physical dependency of the adult with learning disabilities

v) the carers' satisfaction with informal support

vi) the emotional support available to the carer

vii) the formal support available to the carer.

To control for any differences in well being due to the demographic characteristics of the adult with learning disabilities and of the parental carer, these variables were entered in to the regression as two separate blocks first. The remaining independent variables, the challenging behaviour and physical dependency of the adult with learning disabilities, and the supports available to the carer (informal, emotional, and formal support), were then added as a third block, using the stepwise method of entry. The results of the multiple regressions are presented in Table 6.

From Table 6, the models for the negative measures of well being were significant at or beyond the .001 level, with approximately half of the variance of these measures explained by the independent variables. With the positive measures of well being, the variance explained by the independent variables was less, just over one third, with the models being significant at the 0.05 level. Three of the seven variables were related to parenting stress, with two related to anxiety, depression and positive affect. Only one variable related to psychological well being.

Table 6. Hierarchical multiple regression analyses of parental well being.

Variable	R2	R2 change	F value for R2 change	Overall F value
Positive affect				
Demographics of awld	0.15	0.15	2.51	2.51
Demographics of parental carer	0.20	0.05	0.53	1.27
Informal support	0.31	0.11	8.29**	2.07*
Physical dependency	0.38	0.06	4.84*	2.45*
Parenting stress				
Demographics of awld	0.11	0.11	1.79	1.79
Demographics of parental carer	0.22	0.11	1.17	1.43
Challenging behaviour	0.41	0.19	15.69***	3.10**
Physical dependency	0.49	0.08	8.26**	3.94***
Informal support	0.57	0.08	8.36**	4.82***
Anxiety a				
Demographics of awld	0.13	0.13	1.97	1.97
Demographics of parental carer	0.30	0.17	1.83	1.97
Informal support	0.45	0.15	12.10**	3.32**
Challenging behaviour	0.51	0.07	6.03*	3.89***
Depression b				
Demographics of awld	0.10	0.10	1.52	1.52
Demographics of parental carer	0.27	0.17	1.10	1.75
Challenging behaviour	0.45	0.18	14.62***	3.38**
Informal support	0.50	0.06	5.02*	3.79***
Psychological well being c				
Demographics of awld	0.11	0.11	1.61	1.61
Demographics of parental carer	0.27	0.16	1.64	1.67
Emotional support	0.34	0.07	4.99*	2.10*

Note. Awld = adult with learning disabilities. N= 62, apart from a = 57 (missing data & one outlier excluded); b=58 (missing data);c=57(missing data).
*p<0.05,**p<0.01,***p<0.001.

The amount of variance associated with each independent variable differed for the five well being measures. Of note, challenging behaviour is related to the negative outcomes of well being, explaining almost an additional fifth of the variance in parenting stress (19%) and in depression (18%), and an additional 7% in anxiety. Satisfaction with informal support is also related to all of the measures of negative well being (additional variance accounted for ranging from 6-15%), as well as to positive affect (11% additional variance accounted for). Physical dependency also contributes moderately to positive affect (6% additional variance accounted for) as well as to parenting stress (8%). Emotional support is a moderate contributor to psychological well being (7% additional variance accounted for). Formal support, the demographic characteristics of the adult with learning disabilities and those of the carer do not contribute to any of the measures of well being.

Respite care

The means, standard deviations and possible range of scores of the respite care

satisfaction variables and respite care use variables, are presented in Tables 7 and 8.

Table 7. Respite care satisfaction variables

Rating of:	Mean score	SD	Range of scores
Satisfaction with planning/discussion	3.54	0.81	1-4
Satisfaction with respite care	3.44	0.81	1-4
Extent to which needs are met	3.46	0.74	1-4
Quality of respite care	3.33	0.81	1-4

Table 8. Respite care use variables

Measure	Mean score	SD	Range of scores
Recency (last use, weeks ago)	7.11	9.31	1-12
Length of use of service (years)	4.54	2.99	0-12
Amount (days in a year)	26.4	12.9	2-48
Frequency (number of times use per year)	6.99	3.48	1-12

i) Are parents satisfied with the respite care that they receive?

The information presented in Table 7 suggests that there is a high level of satisfaction

with all aspects of respite care services, (the planning of the stay, the quality of the

care received, the respite service received and the extent to which parents' needs are met).

On examining these variables more closely, 85.5 % (n=53) of parents reported that they were mostly or very satisfied with the planning of their son/daughter's stay; 82.0% (n=50) parents reported that they rated the quality of their son/daughter's respite stay as good or excellent; 85.5% (n=53) of parents were mostly or very satisfied overall with the respite care service; and 87.1% (n=54) parents stated that most of not all of their needs were met as a result of using the service.

Parents using family based respite care were significantly more satisfied with each aspect of respite care use than parents using respite care units, (planning, $t(52)=4.55$, $p<0.001$; quality of care, $t(52)=6.84$, $p<0.001$; whether their needs were met, $t(52)=5.60$, $p<0.001$; overall satisfaction with respite care, $t(52)=5.60$, $p<0.001$). However, the low number of parents using family based respite care (8), compared with 53 parents using respite care units, may invalidate this finding.

<u>ii) Is respite care use associated with parents' well being?</u>

Table 9 shows the correlations between the respite care use and variables and the measures of parental well being.

Table 9. Correlations of respite care use variables with parental well being measures

Measure	Positive affect	Parental stress	Anxiety	Depression	Psychological wellbeing
Use variables					
Recency	0.00	0.04	0.07	-0.01	0.07
Length of use	0.02	-0.09	-0.10	-0.14	-0.01
Amount	-0.09	0.00	-0.09	0.08	-0.13
Frequency	-0.11	-0.01	-0.02	0.09	-0.26

*p<0.05, **p<0.01, ***p<0.001

There are no significant correlations between any of the respite care use variables and the well being of the parental carer. The correlations between these two groups of variables are very low.

iii) What do parents see as the benefits of respite care?

The responses to the open ended question, 'In what ways, if any, is using respite care beneficial for you?' fell into five categories: giving carer a break, beneficial for offspring not for carer, beneficial for carer and for offspring, preparation for long-term care, and not beneficial for either carer or offspring.

Giving carer a break

The majority, 80.6% of parental carers saw respite care as 'giving them a break'. Responses frequently incorporated the concept of being free from clockwatching. As one parent said: "The freedom to be able to go out when we want to go out, come

home when we want and not have to rush...you're always timing yourself, having to be

back for 4p.m....even though you'd like to spend more time out. We're always

conscious of the time". (P7) And another: "It gives me a break, I don't have to look at

the clock. I can go out and please myself if I want to. I don't have to do anything for

her". (P30)

Other parents made reference to having a chance to lead a normal life and to recharge

their batteries: "To give us a 'normal life', to be able to relax. She is very dominating,

she wants things done on the spur of the moment, we can't relax or settle as she'll

suddenly scream. We're on edge all the time....wondering what she'll do next. When

she's away on respite things are back to normal.....I can put things back in the right

place. I can recharge my batteries."(P11)

However other parents spoke about how difficult it is to get used to the time that

respite provides: "It means I don't have to be at home at 3.30 p.m. and 9.45 a.m.,

when she goes or comes back from the centre. It means that I can go out at 3 or 4 p.m.

and not worry about being back. I've got more freedom to do whatever I want to do.

But after 50 years those times are engrained in me, so it's difficult to let go of that. But

it does mean that I can be more spontaneous".(P34) And another: "Obviously it gives

me a break. Two or three days away though is not really enough time to get adjusted

to having your own time. I still keep one eye on the clock."(P49)

Not beneficial for carer, only for offspring

Four parents (6.5%) reported that using respite care was not beneficial for them but that it was only beneficial for their son/daughter: " It's not really that beneficial as she's not that hard work...it's beneficial for her..she has some independence, has to do more for herself. I use it more for her than for me. She enjoys it".(P35)

The remaining responses were that respite care was beneficial for both the parent and the adult with learning disabilities (4.8%, n=3), that respite care was used as preparation for long-term care, (4.8%, n=3) and that respite care use was not beneficial for either parent nor the adult with learning disabilities (3.2%, n=2).

Summary

Overall it seems that parents are very satisfied with the respite care that their offspring receive. Use of respite care is not associated with parental wellbeing, with none of the respite care use variables significantly correlated with parental outcome measures. However, the qualitative data, indicate that the main effect of respite care is enabling parents to have a break from their relative and the caring role.

4) Is the salience that parents place on the post parental life style (whether parents are 'captive' or 'captivated') related to their wellbeing ?

The final research question was more exploratory and sought to determine whether the salience that parents place on a post parental lifestyle for themselves - whether they

were 'captive' or 'captivated' parents - was related to their well being. The responses to the open ended question, 'How different do you think your life would be if *(name)* was not living at home?' were coded into three categories: captive, captivated and unsure (if the response did not clearly fit either group). Two raters independently coded the data and obtained good inter-rater reliability (Cohen's kappa = 0.78).

Captive parents

Just under a third of responses (29%, n=18) were coded into the 'captive' group. 'Captive parents' are those who experience the tasks of parenting as restricting and as tasks they would like to give up; they desire the lifestyles enjoyed by their peers whose children had left home. References to freedom were prominent: "I would be free as a bird. There would be no stress with him not being here. My life is run around him - he dominates my whole life".(P1) The feeling of being a prisoner as a result of their current situation was also salient: "Totally different, my life would be totally different, sometimes this doesn't feel like my home, it feels like a prison. I never go out in the evening, as I can't get a sitter. I go out for the night four or five times a year. What I'm doing every day revolves around her e.g. shopping, running errands, meetings at the day centre. It's like doing a life sentence. I can't be spontaneous with her...I don't know what to do if my health doesn't improve"(P10)

Their awareness of and yearning for a post parental lifestyle was highlighted by the use of respite care: "When she goes away on respite, you get an inkling of what life could be like. You can go out, do what you want to do. It's freedom basically. Silly little things that other people take for granted, like going on the top deck of the bus and

looking at the Thames Barrier. I could lead a more normal life if she wasn't here. It's a normal life...if we wanted to go out, we can just go..it's normality"(P38)

Captivated parents

Over half the responses (61.3%, n=38) were coded as 'captivated'. 'Captivated parents' are those who have relinquished their personal aims and found enhanced positive meaning in their parental role; they hold fewer ambitions to have lifestyles more like their peers. Such parents are aware that without their parenting role they had few other, or no other, roles in which they could invest themselves and their time. 'Captivated parents' reaction to the experience of respite care is one where 'freed time' is seen as 'waiting'. As one parent said: "This is the second week she's been away now....for the first couple of days I don't mind, I do things that I can't do if she was here. Then three or four days into it, I get fed up...I feel a bit lost. I'm a bit bored now".(P28) And another: "I don't know...if they take him away from me now, I'd be quite miserable. Even when he's in respite care and my other sons are out it's dead without him". (P37)

Another parent spoke of her worries of thinking about a post parental life style for herself: " I never think about that. If you think that then your caring for him is reduced. If you think like that then you run the risk of becoming unhappy. If I think about the things that I'm missing then I will become unhappy. So I don't think like that. I'm needed by him....that makes me happy. If he doesn't need me, who would need me? I would be lonely without him".(P42)

The remaining 9.7% (n=6) of responses were coded as unsure, as the responses did not

clearly fit into either group.

Table 10 presents the mean scores of the 'captive' and 'captivated' parents on the

parental well being measures.

Table 10. Parental well being scores for 'captive' and 'captivated' parents.

Measure	Captive parents mean score	Captivated parents mean score
Positive affect scale	46.38	51.00
Parenting stress	30.44	19.44
Anxiety	0.52	0.27
Depression	0.86	0.60
Psychological well being	172.56	183.05

T-tests were carried out to determine whether the salience that parents place on their

post parental identity is related to their wellbeing. Parents who were rated as being

'captivated' reported significantly lower levels of parenting stress ($t(54)= 4.88$,

$p<0.001$), and significantly lower levels of anxiety ($t(50)=2.13$, $p<0.05$) than those

rated as 'captive'. Although there are no statistically significant differences between

the mean scores of 'captivated' and 'captive' parents on the remaining parental well

being measures there is a noticeable trend where 'captivated' parents scored lower on

the negative measures of well being, and higher on the positive measures of well being.

Chapter Four

DISCUSSION

Overview

This chapter begins with a brief summary of the research questions, methods and main findings of this study. The findings are then interpreted in the context of the research questions, the literature explored in chapter one, as well as other areas of psychological literature which enhance an understanding of the findings. The limitations of the study are described, and some suggestions for further research are made. Finally, the theoretical, practical, professional and clinical implications of this study are outlined.

Summary of the aims, methods and findings

This study had two main aims, to explore parents' experiences of caring for their adult offspring with learning disabilities at home and the factors contributing to their experience, as well as to explore the role of respite care in the parental caring experience. Parents using three different respite care services were approached, with the researcher visiting 62 parents in their homes. Structured interviews encompassing mainly quantitative measures, were carried out with the participants.

Overall, participants in this study were not functioning as well as other caregivers and the general population. There was variation in parents' care giving experiences with the majority reporting some stresses in their care giving role, and a minority reporting no stress. There was also variation in parents' experiences over time, with some parents finding their care giving role harder over time and others reporting that it was easier. Various factors were found to be associated with the positive and negative outcomes of parental well being. Overall parents were satisfied with respite care services, although there was no association between respite care use and parental well being. Parents did however feel that respite care was beneficial, predominantly in enabling them to have a break from the care giving role. Finally, the salience that parents place on their post parental life style, whether they were captive or captivated parents, was significantly associated with some aspects of parental well being.

Interpreting the findings

This section is divided into four parts, with the results of each research question interpreted in turn.

<u>Parents of adults with learning disabilities; their experiences of caring</u>

Comparison of the quantitative data with the means and norms from previous studies suggested that, these parents are not functioning as well as other caregivers and the general population. Although it was not possible to determine the statistical significance of these differences due to a lack of information about the comparison

data, this finding provides very preliminary support for the 'wear and tear' hypothesis of care giving (Townsend et al., 1989); that on average family care giving has a negative effect over time on the caregiver's mental health, more than on others their age. The qualitative data regarding parents' experiences over time, with just under half of all parents reporting that care giving was harder now than when their offspring were younger, also indicates some preliminary support for the 'wear and tear' hypothesis.

The quantitative results of this study are however subject to the methodological drawbacks of previous studies, in that the cross sectional nature of the study means that data are only available based on the later years of life span. There are no comparisons made between the carers present levels of functioning and the pattern manifested by these families when they were younger. This, as well as the lack of information available on the comparison groups, suggests that these results should be interpreted with caution.

These results however, contradict the existing research in the literature which provides preliminary support for the 'adaptational hypothesis', that over time parents have adapted to their care giving role (Cameron et al., 1991; Krauss & Seltzer, 1993; Seltzer & Krauss, 1989). An alternative explanation for the results of previous research is that the samples were 'positively biased', that those parents who experienced high levels of stress in their care giving role (i.e. 'wear and tear'), have placed their offspring out of home. Therefore only those parents who have 'adapted' to the care giving role were part of the research studies. One possible explanation for the different findings of this study is that the current sample is not so 'positively biased', that

parents who experience 'wear and tear' have not placed their offspring out of home. This may be due to a number of possible reasons, including differing government policies, service philosophies, and various socio-economic grounds.

The mean scores and the range of scores on the positive measures of parental well being in this study, indicate that there are positive outcomes of caring for parents. This provides support to the increasing awareness of the positive outcomes of caring for carers (Pruchno, 1990; Smith, 1996), and consequently to the argument of moving away from the 'pathological' view of care giving (Byrne & Cunningham, 1985). It also provides support to the notion that care giving is an act of mixed valence for caregivers; that care giving has both positive and negative outcomes (Bristol & Schopler, 1984).

The qualitative data on parents' current experiences highlight the variation in the care giving experience for parents, with some parents reporting care giving as stressful, and others not. This variation and the variation in parents' experiences over time is important to note, as it highlights the diversity and individuality of the care giving experience for parents.

Overall, it is therefore not possible to conclude whether parents have 'adapted' to their care giving role or are suffering from 'wear and tear'. It is possible however to state that there is a variation in the parental caregivers' experiences, with some parents 'adapting' to the role and others not, as well as the fact that care giving has both positive and negative outcomes for carers.

<u>The factors associated with positive and negative outcomes of care giving.</u>

Challenging behaviour was an important factor in relation to the negative measures of

parental well being (parenting stress, anxiety and depression), with higher levels of

challenging behaviour associated with more negative parental well being. Challenging

behaviour had a significant and in most cases large contribution to the variance in these

measures. The results of this study support the existing research literature (Grant &

McGrath, 1990; Greenberg et al., 1993) documenting the role of challenging behaviour

in influencing parental experiences, and highlight the critical role that challenging

behaviour has for care giving parents. The physical dependency of the adult with

learning disabilities was moderately related to the variance in parenting stress and

positive affect, with more dependent offspring associated with higher levels of

parenting stress and lower levels of positive affect between parents and their offspring.

This finding is in accordance with previous research (Seltzer & Krauss, 1989).

The role of support in mediating the well being of parental caregivers has also been

debated in the literature. The results of this study suggest that informal support, rather

than any other type of support (formal or emotional), is associated with parental well

being. Informal support made a significant contribution to the variance of the negative

measures of well being, as well as a moderate contribution to one of the positive

measures of well being (the positive affect between the parent and offspring).

Interestingly, formal support was not significantly related to any of the measures of

well being. These results support much of the previous research in the literature which

emphasise the importance of informal support, and the apparent lack of effect of

formal support on parental well being (Seltzer & Krauss, 1989; Smith et al., 1994).

These findings clearly contradict the assumption that formal services enable families to

continue to care for a dependent member by improving the well being of care giving

families (Krauss, 1986). One possible explanation for these results is the effect of the

documented reduction in formal support for families of adults with learning disabilities

(Suelzle & Keenan, 1981; Todd et al., 1993). Such a reduction may mean that parents

increase if not the amount, then the quality of support they obtain from other sources,

to 'fill' the gap left by formal support services. Such alternative sources of support,

e.g. informal and emotional, may then take on an increased importance and usefulness

for parents with the result that formal supports become less useful. Such a hypothesis

could be explored by adopting a longitudinal approach in exploring variations in the

amount and parental satisfaction with formal and informal support and their

associations with parental well being over time.

Interestingly, neither the demographic characteristics of the carer, nor of the adult with

learning disabilities were associated with parental well being. Existing research (Seltzer

& Krauss, 1989) suggests that demographic characteristics of the carer are strongly

related to the well being of the carer, whereas demographic characteristics of the adult

with learning disabilities are strongly related to carer stress and burden. In particular

parental well being was unrelated to the diagnosis of the adult with learning disability.

Previous research (Seltzer & Krauss, 1989; Seltzer et al.,1993) suggests that parents

of adults or children with Downs syndrome function more favourably than parents of

adults or children whose disability is due to other causes. One possible explanation for

the absence of this finding in this research is the small number of adults with Downs

Syndrome in this study.

With reference to the regression models for the measures of well being, the independent variables accounted for approximately half of the variance of the negative measures of well being and about a third of the variance of the positive measures of well being. Therefore the variables measured explained more of the variance of the negative measures of well being than the positive measures, as found in previous research (Greenberg et al.,1993). Clearly, there are other factors not measured in this study that contribute to the well being of parents, more so for the positive measures of well being than for the negative measures.

One factor which was not measured in this study which may be an important contributory factor, is the coping resources and strategies of the parental carer. The importance of 'coping' is highlighted in the Process Model of Stress and Coping (Lazarus & Folkman, 1984), which is recognised as a comprehensive model of stress, coping and adjustment (Beresford, 1994). The central tenet is that coping mediates the effects of stress on an individual's well being. The model comprises two sources of coping resources, personal coping resources (physical and psychological variables e.g. physical health and religious beliefs), and socio ecological coping resources (resources found in an individual's environment or social context e.g. social support). Although socio ecological coping resources were measured in this study, there was less emphasis on the personal coping resources of the parental caregiver. These coping resources mediate the ways individuals appraise potential stressors, and the options that are available for the choice of coping strategy. Two broad categories of coping have been

defined: problem-focused and emotion-focused coping. Problem-focused coping

includes cognitive and behavioural problem-solving strategies aimed at altering or

managing the stressor, whereas emotion-focused coping strategies are cognitive and

behavioural efforts to reduce or manage the emotional distress derived from the

stressor.

In studies of caregivers for older persons, emotion-focused coping strategies have been

found to be associated with higher levels of depression and distress (Hayley, Levine,

Brown & Bartolucci, 1987; Kramer, 1993, cited in Seltzer, Greenberg & Krauss,

1995). The relationship between problem-focused coping and mental health outcomes

among caregivers is less clear, with some studies reporting no relationship (Kramer,

1993; Pruchno & Kleban, 1993 cited in Seltzer et al., 1995), and others that problem-

focused coping was associated with better mental health outcomes (Hayley et al.,1987;

Pratt, Schmall, Wright & Cleveland, 1985 cited in Seltzer et al., 1995). The

importance of coping strategies for caregivers of adults with learning disabilities has

been highlighted by Seltzer et al. (1995). They explored the coping strategies used by

mothers of adults with mental health problems and mothers of adults with learning

disabilities. Although no differences in problem-focused coping were found, mothers

of adults with mental health problems used more emotion-focused coping, which

predicted greater maternal depression. For mothers of adults with learning disabilities,

use of problem-focused coping strategies was positively related to maternal well-being.

This finding highlights the importance of coping strategies in the care giving

experience for parents of adults with learning disabilities, particularly when considering

the factors associated with the positive measures of well being.

<u>Respite care</u>

Parental satisfaction with respite care

The overall high levels of satisfaction reported by the parents using the service is in accordance with previous evaluations of community based respite care (e.g. Jawed et al., 1992; Stalker & Robinson, 1994). In agreement with the previous research literature (Stalker & Robinson, 1994), parents using family based respite care were significantly more satisfied with each aspect of respite care use than parents using respite care units. There are a number of important facts to consider when looking at these findings. Firstly, there was a low number of parents who used family based respite care, compared to the majority who used respite care units. Secondly, parents using family based care were evaluating one carer, whom to a certain degree they had chosen to provide respite to their offspring, and with whom they often had very strong relationships. This compares with parents evaluating the respite care units, where they often had no choice about where their offspring went, and often where high staff turnover and shifts, meant that they did not have a strong relationship with their offspring's carer.

In addition, the limited effectiveness of asking respondents global questions concerning levels of satisfaction with welfare services has been noted (Fisher, 1983, cited in Stalker & Robinson, 1994). Such limitations refer to the fact that reported satisfaction with services may be less a reflection of service efficacy, but more indicative of low expectations of services (Shaw, 1984, cited in Todd & Shearn, 1996b). For many

parents their use of respite care services was restricted to the service they are currently using. Their ratings of satisfaction were therefore often confined to knowledge of just one service, and may well be indicative of low expectations of services. Additionally the lack of options and choice for many parents of alternative respite care services, may have resulted in high satisfaction ratings, for fear of voicing their dissatisfaction, and the consequent possibility of less favourable access to respite care services.

Association between respite care use and parents' well being

Respite care use does not appear to be associated with parental wellbeing, with none of the respite use variables significantly correlated with parental outcome measures. This finding suggests that the use of respite care does not lead to increased well being of the parental carers. This supports a small number of studies suggesting no direct link between family well being and respite care use (Joyce, Singer & Isralowitz, 1983), as well as the results outlined earlier indicating a lack of role for formal support services in the parental experience. The qualitative data on the benefits of respite care for parents indicate that parents report the main effect of respite care as enabling them to have a break from caring for their relative. This suggests that there are benefits for parents in using respite care which are not reflected by the results of this study, and supports previous research indicating that respite care is valued by parents (McGrath & Grant, 1990; Tyndall, 1987).

However there are a number of methodological drawbacks to this study, some of which were outlined in chapter one, which may explain why the results of this study did not indicate any association between respite care use and parental well being.

Although multiple measures of parental well being were used in this study, the design would have been strengthened by adopting a longitudinal approach, and administering the measures over time i.e. prior to, during, just after a respite care stay and at increasing periods of times after the respite care stay. Due to resource and time constraints of the study however, this was not possible.

The outcome measures used focused on parental well being and the relationship between the parent and the offspring. From the qualitative data, parents report the benefits of respite as enabling them to have a break from the caring role, as giving them freedom and an opportunity for a 'normal life', the opportunity to do different things. This indicates that other outcome measures may demonstrate a significant association with respite care, e.g. changes in activity patterns, as measured by Botuck and Winsberg (1991).

What do parents see as the benefits of respite care?

In accordance with previous research (Sholl, Saunders & Radburn, 1991; Stalker & Robinson, 1994), the overwhelming response of parents as to the benefits of respite care is the opportunity to have a break from the caring role. The proportion of parents reporting this as a benefit in this study was higher than in previous research, with a few other benefits reported (i.e. beneficial for their offspring, beneficial for both carers and offspring). Although parents were asked about the benefits of respite care, some commented on the time made available to them as being insufficient and too inflexible to reduce their sense of burden, (as noted elsewhere, Todd & Shearn, 1996a; 1996b). The freed time made available by respite care was extremely valued by parents, but it

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often failed to provide sufficient time to engage in activities at the same times as their peers (as noted by Todd & Shearn 1996a). This provides possible further explanation as to the lack of association between respite care use and parental well being.

Is the salience that parents place on the post parental life style (whether parents are 'captive' or 'captivated') related to their wellbeing ?

The qualitative data provided support to the notion of 'captive' and 'captivated' parents as described by Todd & Shearn (1996 a; 1996b; 1996c), with many of the themes identified for each group apparent in the responses given by this sample. Phrases such as 'being a prisoner', 'of not being free' were prominent in the responses of 'captive' parents as was an awareness of and a yearning for a post parental lifestyle highlighted by the use of respite care. With 'captivated' parents, the lack of alternative roles to the parenting role and their reactions to respite care, where 'freed time' is experienced as 'waiting' were also apparent. This distinction of two groups among the parental carers also supports the notion that there is variation in parents experiences of caring for their offspring with disabilities, as described earlier within this chapter.

The exploratory research questions focusing on post parental identity and its relationship with parental well being, indicated that the salience parents place on their post parental identity is associated with parental stress and anxiety, with 'captive' parents reporting significantly higher levels of parental stress and anxiety. Although the differences between the captive and captivated groups were not statistically significant for the remaining parental well being measures, there was a notable trend with,

'captive' parents scoring higher on the negative measures of parental well being, and 'captivated' parents scoring higher scores on the positive measures of well being. These results provide some support for the hypothesis that 'captive' parents have more negative outcomes within their caring experience, and 'captivated' parents more positive outcomes. This suggests that post parental identity is a potentially important factor associated with parental well being.

Limitations of the study

The limitations of the study can be discussed in terms of generalisability, the research design and the measures used.

Generalisability of the findings

The limits to the external validity of the findings in this study result from the restricted sample of participants. Although a high proportion of those contacted agreed to take part in the study, there was still a proportion of parents who chose not to take part. It is uncertain whether those parents who chose not to take part were similar or different to those who did take part. In order to address the role of respite care in the caring experience, parents contacted to take part in the study used respite care and consequently were in contact with services. Those parents who do not use respite care, and those who do not use services at all, may have very different experiences of caring for their offspring. The results of this study suggest however that formal support, and respite care had minimal associations with parental wellbeing. This suggests that those

who are not in contact with services, or who do not use respite care, may have similar experiences to those who did take part in the study.

The sample of participants consisted almost entirely of mothers rather than fathers, caring for their offspring. This appears to be representative of parents caring for adults with learning disabilities, with a large number of studies reporting mothers as the primary carer (Grant & McGrath, 1990; Holmes & Carr, 1991; McGrath & Grant, 1993; Mitchell 1990; Sholl et al., 1991; Todd et al., 1993). Gender has been reported as not significantly distinguishing between caregivers, with male and female caregivers similar in perceptions of their care giving ability, need for services, and plans for service use in the future (Brubaker, Engelhardt, Brubaker & Lutzer, 1989). This suggests that the care giving experience would be similar for male and female caregivers.

All participants who took part in the study lived in South East London. A larger number of participants from a wider geographical area would improve the external validity of the findings. There may well be regional differences in findings, as different areas may have different services available to parents and their offspring. There may also be variations in socio-demographic variables, such as standards of housing, employment and financial difficulties in other parts of Britain. Additionally, the majority of participants were White British. This may also limit the external validity of the findings, with parents from different ethnic groups possibly having different experiences resulting from differing cultural and religious beliefs and expectations.

<u>Research design</u>

This study used a non-experimental, correlational cross sectional design which has

limitations. Cross sectional studies provide a 'snap shot' of the situation for

participants at one point in time. Ideally, it would have been helpful to employ a

longitudinal design, to explore the changes in parents' experiences over time. This

design issue is particularly relevant when exploring parents' experiences of caring for

their adult offspring. As previously mentioned the current study provides information

on the latter years of functioning for parents, with no information available to enable

comparisons between the carers present levels of functioning and the pattern

manifested by them when they were younger. The cross sectional design used may

also have led to particular limitations when considering the association between respite

care and parental well being. As mentioned previously, a longitudinal design measuring

parental well being at multiple points in time i.e. prior to, during, just after and at

increasing lengths of time after respite care use, would have strengthened the design of

the study, and perhaps yielded different results. The limitations of time and resources

prevented the possibility of a longitudinal study.

There are also limitations to the internal validity of the study's findings. Correlational

studies cannot be used to make unequivocal causal inferences about relationships

between variables. It was therefore not possible in this study to move beyond the

strength of associations between variables to make inferences about causality.

As the study was essentially quantitative and structured in nature, a wealth of

qualitative information which could provide in depth information about parents'

experiences of caring for their adult offspring as well as of the role of respite care, was

not recorded. Although parents responses to specific open ended questions were

recorded verbatim, a more qualitative approach would have yielded more in-depth data

about people's constructions of their experiences.

Measures

On reflection there are some aspects of some of the measures which warrant further

discussion.

With respect to the dependent measures, there has been some discussion in the

literature regarding the measure used for parenting stress in this study, the Short-form

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

1983). There are four versions of this scale in research use, with varying numbers of

items and scales. The Friedrich et al., (1983) version was chosen for this study as it

was the shortest version and therefore the quickest to administer, and the version with

the most information concerning it's psychometric properties.

There are a number of criticisms of the measure. Clayton, Glidden and Kiphart (1994)

suggest as the scale measures child characteristics as well as family functioning, that a

high score can be obtained as a result of child having more physical and cognitive

limitations rather than because the family is affected negatively by those physical and

cognitive limitations. They suggest that it is therefore difficult to draw interpretations

about the impact of a child's disability on the family functioning. Glidden (1993) also

reviews all the versions of the QRS highlighting a number of difficulties such as:

definitional problems, multiple measures of the same construct that do not converge,

and failure to replicate. However, these authors do not suggest that the measure be

abandoned, primarily as there is no better measure and also as it has an extensive

research base. Instead, they suggest that it should be used along with other measures

of 'stress', i.e. that multiple measures of 'stress' should be employed, as were in this

study.

Salisbury (1986b) also comments that the QRS-F version excludes the financial stress

component present in the original scale (Holroyd, 1974). She suggests that this factor

is particularly important given the body of research supporting the association of

financial stress and the presence of a disabled family member (Carver & Carver, 1972,

cited in Salisbury, 1986). To compensate for this in this study, a question regarding

financial stress was included in the interview schedule.

Although the majority of research using the QRS-F explores the impact of a disabled

child on family members, this version and others have also been used frequently with

adult populations. Day and Alston (1988) used the measure with caregivers of

physically disabled adults, and Allen, Linn, Gutierrez and Willer (1994) with caregivers

of adults following traumatic brain injury. Much of the research with parents of adults

with learning disabilities also uses this measure (e.g. Krauss & Seltzer, 1993, Seltzer &

Krauss, 1989, Seltzer, Krauss & Tsunematsu, 1993, etc.).

However, there are some aspects of this scale which perhaps need to be adapted when applied to an adult population. Some of the items on the pessimism scale are perhaps more indicative of realism than pessimism when considering adults with learning disabilities, rather than children with learning disabilities. For example, question seven, " I have accepted the fact that *(name)* might have to live out his/her life in some special setting (i.e. group home)" if marked as True, is indicative of pessimism. However, when considering adults with learning disabilities and their elderly parental carers, it is perhaps more appropriately regarded as realism.

Parents sometimes reported that there were other events (e.g. death of family members, illness) that were recent or ongoing events and that at the time of interview it was these events that affected their 'wellbeing', rather than caring for their adult offspring. As a result of their concerns about the source of their 'stress', some parents did not fill out the psychological well being, anxiety and depression questionnaires. These were consequently recorded as missing data.

Some of the measures of independent variables also warrant further discussion. On asking parents about their satisfaction with informal support, the researcher felt there was a sense of asking participants to evaluate their family and friends, as opposed to the support provided by them. The measure of formal support used (the number of services accessed by the adult with learning disabilities), although used in previous studies (e.g. Greenberg, Seltzer & Greenley, 1993) was rather a crude measure. It may have been more useful to measure parental satisfaction with formal support, as well as the amount of support received. An additional source of formal support for parents,

not measured in this study, was the level of professional support received by parents

and offspring (e.g. from social workers, G.P.s, community nurses).

Among the demographic independent variables, parents were asked whether there

were any other offspring living at home. An additional perhaps more useful question

may have been to ask whether the parent was the main carer for anyone else, as well as

their offspring with learning disabilities, for example other children, spouses or parents.

Suggestions for further research

These suggestions broadly parallel the areas of limitations described above.

<u>Generalisability of the findings</u>

In order to increase external validity, it is important to replicate this study with a larger

sample of parents of adults with learning disabilities, across a wider geographical area,

as well as to try and access those parental caregivers who do not use services.

Although gender has been reported as not significantly distinguishing between the

caregivers (Brubaker et al., 1989), it seems important to take into account the views of

both the parental caregivers and to interview both parents where appropriate, about

their experiences, not just the primary caregiver.

Another aim would be to test the generalisability of the findings by seeing whether they

hold true for other groups of parents of adults with learning disabilities; and other

groups of parents caring for adult offspring e.g. with mental health problems, who have physical disabilities.

An additional wider perspective would be to include the views of not only the parental caregivers, but also other family members, such as siblings. The views of adults with learning disabilities themselves, about their experiences of living at home are also vital to try and ascertain. Existing research in this area yields interesting results. In addition to those parents who are supportive to their offspring, other groups of parents are identified such as those who are dependent on their adult offspring and those who are mutually dependent (Walmsey, 1996).

Research design

Longitudinal designs would enable parents' experiences to be explored over time, as well as the effect of respite care over time.

The qualitative data provided by this study, although not analysed formally, provided additional information about the care giving experience for these parents and about the role of respite care in their care giving. A formal analysis of the qualitative data however, would have provided further in-depth information about parents constructions of their experiences of caring for their offspring, as well as the role of respite care in their caring experience. Possible methodologies include discourse analysis (Potter & Wetherell, 1987) and a grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1990); the latter being the methodology employed by

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Todd & Shearn (1996 a; 1996 b; 1996 c) in their studies. Further research should not however, abandon quantitative methods in this area, nor ignore the benefits that adopting a qualitative approach can bring. Instead, adopting a 'methodologically pluralistic' approach, where appropriate methods are employed for the research questions under investigation (Barker, Pistrang & Elliott, 1994) seems the best way forward in increasing our understanding, and enhancing our knowledge about this group of caregivers.

Measures

As well as the adaptations to some of the measures mentioned in the limitations section, it may be useful for further research to include additional measures:

To control for the other events which may be affecting parents well being, it may be useful to incorporate a life events scale (e.g. Holmes & Rahe, 1967) into the interview procedure. The addition of some form of 'control' scale may also enable parents to complete all the questionnaires, knowing that their 'stress' due to other sources was being accounted for by another measure.

In addition as described earlier, other possible independent variables which may be associated with parental well being according to the Process Model of Stress and Coping (Lazarus & Folkman, 1984), are the personal coping resources and coping strategies of the parent. Particularly important personal coping resources may include religious beliefs and personality variables such as optimism, and locus of control

beliefs. Parental coping strategies (problem-focused and emotion-focused) can be measured in a number of ways e.g. the Ways of Coping Checklist (Folkman & Lazarus, 1980), the Multidimensional Coping Inventory (Carver, Scheier & Weintraub, 1989). The concept of 'coping' appears to be vital in gaining a fuller understanding of how parents manage their caring role.

When considering the role of respite care, a broader view of the effects of respite care needs to be taken with respect to the measures used to determine outcome. In particular from this study, one other area which seems pertinent to measure is the activity patterns of the carer.

It is important however, to consider the practical implications of including additional measures into the interview schedule, in terms of the length of the procedure. The thought of a lengthy research interview may discourage parents from taking part in the procedure, and subsequently having undergone a lengthy interview procedure may also discourage parents from taking part in research in the future. Ethically and morally, it is important to balance the needs of research with the well being of the participants and the needs of research in the future.

Implications of the study

The implications of this study for theory, research and practice are outlined.

<u>Theoretical and research implications</u>

The results of this study highlight the importance of examining the experience of parents caring for their adult offspring with learning disabilities and the subsequent role of respite care. It adds to the small but increasing research base for this group of largely forgotten carers.

This study emphasises the variation in parental caregivers' experiences, and highlights the importance of identifying those parents who are adapting to the caring role as well as those who are not, and the consequent contributory factors. This feels to be a more clinically useful research stance to adopt, rather than attempting to conclude that on the whole, parents 'adapt' to the care giving role, or are subject to 'wear and tear'.

The prominence of the positive outcomes of caring for caregivers and the value of researching this aspect of care giving is also highlighted by this study. This emphasises the view that care giving is an activity of mixed valence for carers, contrary to the 'pathological' view of care giving prominent in earlier research.

The importance of parents' post parental identity and it's association with parents well being is also emphasised by the results of this study. This concept would be particularly interesting to explore longitudinally, from birth across the lifespan, to determine whether variations occur across time, and whether stages in the lifestyle are influential in determining parents' identities. This is an important area to research further and has the potential to have widespread theoretical and clinical implications. Further research

should also consider whether the salience that parents place upon their post parental

identity influences the effect of respite care, as hypothesised by Todd & Shearn

(1996b).

Practical, clinical and professional implications

The findings of the study have implications for professionals and staff working with

adults with learning disabilities and their families in all areas, both in planning and in

providing services.

The factors shown to be associated with the positive and negative outcomes of caring

for parents are of particular use for services and service providers. Of importance is

the association between challenging behaviour and the negative outcomes of caring,

and the associations between informal support and physical dependency, and the

positive and negative outcomes of caring. This suggests that to reduce the negative

outcomes and increase the positive outcomes of caring, it is vital services are directed

towards reducing the levels of challenging behaviour in the community, increasing the

avenues for informal support and providing ways for carers to manage the physical

dependency of their offspring.

There are varying ways in which services and professionals can act on this information.

Clinical psychology has a vital role in reducing challenging behaviour, by assessing,

formulating and designing appropriate interventions that can be implemented by

parents. Clinical psychologists and services as a whole have a role in supporting

parents in implementing such interventions at home and elsewhere, and consequently evaluating their effectiveness. It is also vital that services and professionals are aware of the important role of informal support, and that opportunities are facilitated where possible for such support to develop e.g. opportunities for parents to meet each other (without such 'informal' support becoming 'formal'). Services may also be able to alleviate some of the difficulties inherent due to the physical dependency of the adult with learning disabilities, by ensuring that parents have the adaptations and equipment necessary to manage their sons/daughters physical needs, and where appropriate provide extra practical help.

The lack of association between formal support, respite care and parental well being is also striking, and important for services and professionals to note. This is not to suggest that such services should be withdrawn, as parents do value such services, but that the existence of such services alone is not sufficient for parents. Services should work with families and parental caregivers to elicit how they can be more useful to them. In addition, it is important for such services to be aware of those factors indicative of negative and positive outcome, and tailor their services accordingly (as outlined above).

The high level of parental satisfaction with respite services as well as the benefits parents derive from using respite care are important for respite services to note and to feedback to staff.

The variation in caregivers' experiences is also important for services and service

providers to be aware of, that parents may be functioning less well than other adults of their age but that there are also some parents who derive a sense of positive well being from their care giving role. It is therefore important for services and service providers not to presume caregivers experiences, not to 'pathologise' their experience , but to be inquisitive and open minded in ascertaining parents' particular experiences. The salience of the post parental lifestyle for parents are also important to ascertain, due to the possible implications of this for parental wellbeing

This study highlights the experiences of an often undervalued and largely forgotten group of caregivers. One of the potential outcomes of this study would hopefully be to make services and service providers more aware of this group of carers and their experiences, that they receive resources and are involved in service planning and decision making along with other community carers for adults with learning disabilities (e.g. day and residential service staff). Having an awareness of parents' experiences of care giving for their learning disabled offspring throughout their life spans is even more vital when the implications of the current aging population are considered. It is essential that the needs of such caregivers are ascertained, validated and planned for.

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APPENDICES

Appendix 1. Letters sent to prospective participants

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Appendix 10. Definitions of subscales of psychological well being

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Appendix 15. Respite questionnaire

Appendix 1. Letter sent to prospective parents

Sarah Walden
Clinical Psychologist in Training
University College London

November 1997

Dear   ,

You are invited to participate in a study looking at what parents think of respite care, and at how satisfied parents with the respite care that their son/daughter receives. The study also aims to look at the impact on parents of caring for their son/daughter. The information obtained from the study would provide knowledge about what parents think about respite care, about the experience of caring for an adult son/daughter, and the ways in which services could change to provide a better service for parents.

I hope that you feel able to participate in this study. You would be visited at your home by the researcher, at a time convenient to you and if you wish, details of the study would be explained. The researcher would ask some questions about what you think about the respite care your son/daughter receives and whether you are satisfied with further this. You would then be asked to fill in some questionnaires which focus on the impact of caring for your son/daughter and also ask how your son/daughter's needs might affect this impact. There would be no way of identifying you from the information retained, and all information will only be available for the purpose of the study.

This study is independent of any input that you may receive from services at the moment, and as such taking part or not taking part in the study will not affect any services that you currently receive or any that you receive in the future. The opportunity will be available for you to receive feedback on the outcome of the study if you would like.

If you would like any further information at this stage please do not hesitate to leave a message for me at the above telephone number / address and I shall contact you. I shall telephone you in the next few weeks to see if you are interested in taking part.

Thank you for your time in reading this letter.

Yours sincerely,

Sarah Walden
Researcher

Appendix 2: Confirmation letter sent to participants

Sarah Walden
Clinical Psychologist in Training,
University College London.

December 1997

Dear   ,

Following my earlier telephone call regarding the study on respite care and the experience of caring for a relative with learning disabilities, I am writing to confirm that we have made an appointment for me to visit you at your home on
            . I will telephone you nearer the time to confirm this.

As discussed on the telephone, please find enclosed some questionnaires which I would be grateful if you could fill in for me to collect at our meeting. These questionnaires focus on the experience of caring for a relative with learning disabilities. If you wish to talk to me before you fill these in, then we can discuss them when I meet with you. The main focus of our meeting, will be to talk about the respite care your relative receives. The meeting will last one to one and a half hours. As previously mentioned all information is totally confidential, and will only be available for the purposes of the study.

If you have any problems, please do not hesitate to leave a message for me on the above telephone number and I will get back in touch with you.

Thank you in advance for your participation.

Yours sincerely,

Sarah Walden
Researcher

Appendix 3: Letter granting ethical approval

Your Reference
 AJ/CT
Our Reference
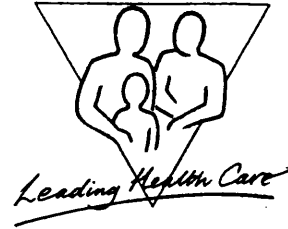
Telephone: 0181 - 333 3000
Ext:
Fax:

THE LEWISHAM HOSPITAL NHS TRUST
RESEARCH ETHICS COMMITTEE

21st May 1997

Sarah Walden
Clinical Psychologist in Training
Sub-department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT

Dear Ms Walden

Title of Protocol: **The impact of caring on parents of adults with learning disabilities, and the role of respite care**

Protocol No: 97/4/6 *(please quote in all correspondence)*

Thank you for your letter of 16th May 1997, and your response to the points we outlined. The revisions you have made are entirely satisfactory, and I am, therefore, happy to give you our approval on the understanding that you will follow the protocol as agreed.

It is your responsibility as the researcher who made the application to notify the Local Research Ethics Committee immediately you become aware of any information which could cast doubt upon the conduct, safety or an unintended outcome of the study for which approval was given.

If there are amendments which, in your opinion or opinion of your colleagues, could alter radically the nature of the study for which approval was originally given, a revised protocol should be submitted to the Committee.

Members of the Committee would like to know the outcome of the study and therefore ask that a report or copy of the results is sent to the secretary in due course.

Yours sincerely

Annette Jeanes
Vice Chair

Appendix 4: Consent form

CONSENT FORM

I have read the letter outlining the study, and spoken to the researcher. I have understood details about what participating in the study involves.

I am aware that all information will be treated confidentially, and used for the purpose of the study.

Name...

Signature...

Date................................

Appendix 5: Full interview schedule

RESEARCH INTERVIEW

Thank participant for agreeing to take part in the study.
Give brief outline re: study: looking at parents experiences of caring for adults with learning disabilities, and at the role of respite care, as well as how satisfied parents are with respite care services.
Emphasise confidential nature of study.
Questionnaires sent look at experience of caring, will ask a few further questions about this, but today will focus more on respite care.
Any questions?
Ask participant to sign consent form.

(B) Open ended questions re: impact of caring

If I can start by asking a few general questions,
We know that looking after a relative with learning disabilities can be stressful, what if any, are the stresses for you?

Have these stresses changed over time, since _____ was a child?

How different do you think your life would be if _____ was not living at home?

(C)Respite questionnaire

I'm now going to ask some questions about how much you use respite care and what you think about the respite care your relative receives. Here is a copy of the questions I will be asking, it may be helpful if you follow them as we go through.

(D) Demographic information

If it's OK, I'm going to ask a few, quick questions about you and your family, which shouldn't take too long.

(1)   How old are you?   _____ years
        (Age of primary carer)

(2) How old is your relative?   _____ years
        (Age of adult with learning disabilities)

(3)   Is there anyone at home that you share the care of _____ with?

        1   yes
        2   no

(4)   If yes, what is your relationship with this person?

        1   partner
        2   son/daughter
        3   sister/brother
        4   mother/father
        5   friend
        6   other_____
        7   not applicable

(5) How old is this person?   _____ years

(6) How would your rate your health?

        0   poor
        1   fair
        2   good
        3   excellent

(7)   How would you rate the health of your relative?

        0   poor
        1   fair
        2   good
        3   excellent

(8) How many siblings does your relative have? _____

(9) How old are the siblings?

_____ years (age 1)
_____ years (age 2)
_____ years (age 3)
_____ years (age 4)

(10)   Do any of the siblings still live at home?

1   yes
2   no

(11)   If so, how many ?   _____

(12)   Are you currently employed?

1   yes
2   no
3   retired

(13)   If yes, what is your occupation?

_____

(14)   If yes, is this full or part time?

1   fulltime
2   part time
3   not applicable

(15)   Is your partner employed?

1   yes
2   no
3   retired
4   not applicable

(16)   If yes, what is the occupation of your partner?

_____

(17)   If yes , is this full or part time?

1   full time
2   part time
3   not applicable

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I'm just about to ask about your financial situation. The reason for this, is that previous research suggests that if people experience any financial difficulties, then this often can be an added worry and concern. If you do not wish to answer the question, that's OK.

(18)   Do you experience any financial difficulties?

1   yes
2   no

(19)   Which ethnic group would you classify your relative as belonging to?

1   African (including black people of African descent born in Britain)
2   Afro Caribbean (including black people of Afro Caribbean descent born in Britain)
3   Asian (including Indian, Pakistani, AfroCaribbean people of Asian descent born in Britain)
4   East Asian (including Chinese and Korean)
5   Arabic
6   Irish
7   White British
8   Vietnamese
9   Turkish
10   European (or Scandinavian)
11   Portuguese
12   Other (please specify)
13   Not known

(20)   What is the diagnosis (if any) given to your relative?

1   cerebral palsy
2   epilepsy
3   autism
4   downs syndrome
5   other
6   not known

(SUPPORT QUESTIONS)

(21) What is your relative's current use of day-time/evening services? (Amount of **formal support** received)

1   stays at home (i.e. no use of services)
2   attends a day centre
3   is employed
4   does voluntary work
5   attends evening activities
6   other (please specify) _____

(22) Have you any friends or family outside the home, that you feel you can rely on to provide you with support? (Prompt: come round and sit with your relative when you want to go out; take your relative out for a period of time....)

1   yes
2   no

(20) If yes, what kind of support do they provide?

_____

_____

_____

(21) How satisfied are you with this support? (**Satisfaction with informal support** received)

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

I'm now going to ask some questions about whether you feel you have people you can talk to about your feelings and problems.

(22)   **Emotional support questionnaire:**
          (Hand copy of questionnaire to participant)

(I).   Have you been able to talk about your feelings and problems with at least
one   friend during the past month?

5   I could always talk freely about my feelings
4   I usually could talk about my feelings
3   About half the time I felt able to talk about my feelings
2   I usually was not able to talk about my feelings
1   I was never able to talk about my feelings

(ii) Have you been able to talk about your feelings and problems with at least one of your relatives in the last month?

5   I could always talk freely about my feelings
4   I usually could talk about my feelings
3   About half the time I felt able to talk about my feelings
2   I usually was not able to talk about my feelings
1   I was never able to talk about my feelings

If appropriate:

(iii). Have you been able to talk about your feeling and problems with your spouse or partner in the last month?

5   I could always talk freely about my feelings
4   I usually could talk about my feelings
3   About half the time I felt able to talk about my feelings
2   I usually was not able to talk about my feelings
1   I was never able to talk about my feelings

(E) Experience of caring

If I could ask you to fill in another brief questionnaire, which looks at people's moods.

Anxiety and depression sub scales of the SCL-90 (23 items)	Levels of anxiety and depression.

(E) Factors influencing impact of caring on carers.

I'd like to ask some questions about your son/daughter, about how independent he/she is, and about how much you have to do to support him/her.

Questionnaire	Construct examined by the questionnaire
Degree of dependency rating scale (derived from Kushlick, Blunden & Cox 1978)	Level of dependence of adult with learning disabilities
A checklist of challenging behaviour (Harris, Humphreys & Thomson 1994)	Level of challenging behaviour of adult with learning disabilities

Appendix 6: Positive Affect Scale

POSITIVE AFFECT SCALE

Below is a list of questions asking about **YOUR RELATIONSHIP WITH YOUR SON / DAUGHTER..** For each question, circle the number and response that best answers the question.

(I). How well do you feel your son/daughter understands you?

1. Not well   2. Not too well   3. Some   4. Pretty well   5. Very well   6. Extremely well

(ii). How well do you feel your son/daughter trusts you?

1. Not well   2. Not too well   3. Some   4. Pretty well   5. Very well   6. Extremely well

(iii). How fair do you feel your son/daughter is towards you?

1. Not fair   2. Not too fair   3. Some   4.Pretty fair   5. Very fair   6. Extremely fair

(iv). How much respect do you feel you get from your son/daughter?

1.Not much   2.Not too much   3.Some   4.Pretty much   5.Very much   6.Extremely much

(v). How much affection do you feel your son/daughter has for you?

1.Not much   2.Not too much   3.Some   4.Pretty much   5.Very much   6. Extremely much

(vi). How well do you understand your son/daughter?

1. Not well   2. Not too well   3. Some   4. Pretty well   5. Very well   6. Extremely well

(vii). How much do you trust your son/daughter?

1.Not much   2.Not too much   3.Some   4.Pretty much   5.Very much   6.Extremely much

(viii). How fair do you feel you are towards your son/daughter?

1. Not fair   2. Not too fair   3. Some   4.Pretty fair   5. Very fair   6. Extremely fair

(ix). How much do you respect your son/daughter?

1.Not much   2.Not too much   3.Some   4.Pretty much   5.Very much   6.Extremely much

(x). How much affection do you have towards your son/daughter?

1.Not much   2.Not too much   3.Some   4.Pretty much   5.Very much   6.Extremely much

Appendix 7: Questionnaire on resources and stress

RESOURCES AND STRESS QUESTIONNAIRE

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

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

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

3. Our family agrees on important matters.   T   F

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

24. There are many places where we can enjoy ourselves as a family when ---------- comes along.   T   F

25. --------------- is over protected.   T   F

26. --------------- is able to take part in games or sports.   T   F

27. --------------- has too much time on his/her hands.   T   F

28. I am disappointed that ------------ does not lead a normal life.   T   F

29. Time drags for ----------------, especially free time.   T   F

30. ---------------- can't pay attention very long.   T   F

31. It is easy for me to relax.   T   F

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

33. I get almost too tired to enjoy myself.   T   F

34. One of the things I appreciate about ------------ is his/her confidence.   T   F

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

36. ----------------- is able to go to the bathroom alone.   T   F

37. --------------- cannot remember what he/ she says from one minute to the next.   T   F

38. ---------------- can ride a bus.   T   F

39. It is easy to communicate with ---------------.   T   F

40. The constant demands to care for ------------- limit my growth and development.   T   F

41. ----------------- accepts him/herself as a person.   T   F

42. I feel sad when I think of ----------------.   T   F

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

44. People can't understand what ----------- tries to say.   T   F

45. Caring for ----------------- puts a strain on me.   T   F

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

47. ---------------- will always be a problem to us.   T   F

48. ---------------- is able to express his/her feelings to others.   T   F

49. ---------------- is able to use a toilet.   T   F

50. I rarely feel blue.   T   F

51. I am worried much of the time.   T   F
52. ---------------- can walk without help.   T   F

Appendix 8: Symptom checklist -90-revised

MOOD QUESTIONNAIRE

Below is a list of problems and complaints that people sometimes have. For each item, select the number that best describes **HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST MONTH INCLUDING TODAY.** Write one number in the space to the right of each word.

The numbers refer to these phrases:
0 = Not at all
1 = A little bit
2 = Moderately
3 = Quite a bit
4 = Extremely

1. Nervousness or shakiness inside..._____

2. Feeling tense or keyed up.._____

3. Feeling low in energy or slowing down..._____

4. The feeling that something bad is going to happen to you............_____

5. Trembling..._____

6. Crying easily..._____

7. Feeling of being caught or trapped.._____

8. Suddenly scared for no reason..._____

9. Blaming yourself for things..._____

10. Feeling lonely.._____

11. Feeling blue.._____

12. Worrying too much about things..._____

13. Feeling no interest in things..._____

14. Feeling fearful..._____

15. Heart pounding or racing.._____

16. Feeling hopeless about the future.._____

17. Feeling everything is an effort.._____

18. Spells of terror or panic.._____

19. Feeling so restless you couldn't sit still......................................._____

20. Feelings of worthlessness..._____

21. Thoughts of ending your life..._____

22. Thoughts and images of a frightening nature................................._____

Appendix 9: Scales of psychological well being

WELL BEING QUESTIONNAIRE

This questionnaire asks questions about how you see your life. Below are a list of statements. For each statement, please select the number that best describes **HOW MUCH YOU AGREE WITH THE STATEMENT.** Write one number in the space to the right of each word.

The numbers refer to these phrases:
1 = Strongly disagree 2 = Disagree 3 = Disagree slightly 4 = Agree slightly 5 = Agree 6 = Strongly agree

1. In general, I feel I am in charge of the situation in which I live..................._____

2. I am not interested in activities that will expand my horizons........................_____

3. I feel good when I think of what I've done in the past and what I hope to do in the future.._____

4. The demands of everyday life often get me down.._____

5. In general, I feel that I continue to learn more about myself as time goes by..._____

6. I live life one day at a time and don't really think about the future................._____

7. I do not fit very well with the people and the community around me..............._____

8. I am the kind of person who likes to give new things a try............................._____

9. I tend to focus on the present because the future nearly always brings me problems..._____

10. I am quite good at managing the many responsibilities of my daily life........._____

11. I don't want to try new ways of doing things-my life is fine the way it is......_____

12. I have a sense of direction and purpose in life.._____

13. I often feel overwhelmed by my responsibilities..._____

14. I think it is important to have new experiences that challenge how you think about yourself and the world.._____

15. My daily activities often seem trivial and unimportant to me......................._____

16. If I were unhappy with my living situation, I would take effective steps to change it...._____

17. When I think about it, I haven't really improved much as a person over the years........._____

18. I don't have a good sense of what it is I'm trying to accomplish in life........._____

19. I generally do a good a good job of taking care of my personal finances and affairs.._____

20. In my view, people of every age are able to continue growing and developing.._____

21. I used to set goals for myself, but that now seems like a waste of time........._____

22. I find it stressful that I can't keep up with all of the things I have to do each day.._____

23. With time, I have gained a lot of insight about life that has made me a stronger, more capable person.._____

24. I enjoy making plans for the future and working to make them a reality................._____

25. I am good at juggling my time so that I can fit everything in that needs to get done.._____

26. I have the sense that I have developed a lot as a person over time......................_____

27. I am an active person in carrying out the plans I set for myself............................_____

28. My daily life is busy, but I derive a sense of satisfaction from keeping up with everything.._____

29. I do not enjoy being in new situations that require me to change my old familiar ways of doing things.._____

30. Some people wander aimlessly through life, but I am not one of them................._____

31. I get frustrated when trying to plan my daily activities because I never accomplish the things I set out to do.._____

32. For me, life has been a continuous process of learning, changing, and growth........_____

33. I sometimes feel as if I've done all there is to do in life......................................_____

34. My efforts to find the kinds of activities and relationships that I need have been quite successful.._____

35. I enjoy seeing how my views have changed and matured over the years................._____

36. My aims in life have been more a source of satisfaction than frustration to me......._____

37. I have difficulty arranging my life in a way that is satisfying to me.........................._____

38. I gave up trying to make big improvements or changes in my life a long time ago.._____

39. I find it satisfying to think about what I have accomplished in my life....................._____

40. I have been able to build a home and a lifestyle for myself that is much to my liking.._____

41. There is truth to the saying you can't teach an old dog new tricks ...._____

42. In the final analysis, I'm not sure that my life adds up to much............................._____

Appendix 10: Definitions of subscales of psychological well being

DEFINITIONS OF SUB SCALES OF PSYCHOLOGICAL WELL BEING (RYFF, 1989)

Environmental Mastery:

High scorer: Has a sense of mastery and competence in managing the environment; controls complex array of external activities; makes effective use of surrounding opportunities; able to choose or create context suitable to personal needs and values.

Low scorer: Has difficulty managing everyday affairs; feels unable to change or improve surrounding context; is unaware of surrounding opportunities; lacks sense of control over external world.

Purpose in life:

High scorer: Has goals in life and a sense of directedness; feels there is meaning to present and past life; holds beliefs that give life purpose; has aims and objectives for living.

Low scorer: Lacks a sense of meaning in life; has few goals or aims, lacks sense of direction; does not see purpose of past life; has no outlook or beliefs that give life meaning.

Personal growth:

High scorer: Has a feeling of continued development; sees self as growing and expanding ; is open to new experiences ; has sense of realizing his or her potential; sees improvement in self and behaviour over time; is changing in ways that reflect more self-knowledge and effectiveness.

Low scorer: Has a sense of personal stagnation; lacks sense of improvement or expansion overtime; feels bored and uninterested with life; feels unable to develop new attitudes or behaviours.

Appendix 11: Degree of dependency scale

DEGREE OF DEPENDENCY RATING SCALE

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(1) Continence:

a. Wetting (nights)	1 Frequently	2 Occasionally	3 Never
b. Soiling (nights)	1 Frequently	2 Occasionally	3 Never
c. Wetting(days)	1 Frequently	2 Occasionally	3 Never
d. Soiling (days)	1 Frequently	2 Occasionally	3 Never

(2) Mobility:

e. Walk with help	1 Not at all	2 Not up stairs	3 Upstairs and elsewhere
f. Walk him/herself	1 Not at all	2 Not up stairs	3 Upstairs and elsewhere

(3) Self help:

g. Feeds him/herself	1 Not at all	2 With help	3 Without help
h. Washes him/herself	1 Not at all	2 With help	3 Without help
I. Dresses him/herself	1 Not at all	2 With help	3 Without help

Appendix 12: Checklist of challenging behaviour

CHALLENGING BEHAVIOUR CHECKLIST
RATING SCALES

Frequency

How often has this behaviour occurred during the past three months?

1	=	never	This behaviour has not occurred during the past 3 months.
2	=	rarely	Has occurred during the past 3 months but not in past month.
3	=	occasionally	1-4 times in the past month
4	=	often	More than 4 times in the past month
5	=	very often	Occurs daily or more often

Management Difficulty

How difficult do you find it to manage this situation?

1	=	no problem	I can usually manage this situation without any difficulty at all
2	=	slight problem	I can manage this situation quite easily although it does cause me some difficulty
3	=	moderate problem	I find this situation quite difficult to manage, but I feel confident that I can
4	=	considerable problem	I find it very difficult to manage, but I feel confident that I can
5	=	extreme problem	I simply cannot mange this situation without help

Severity

What were the most serious injuries caused by his behaviour during the past three months?

1	=	no injury	Did not appear to cause pain or tissue damage to other person
2	=	minor injury	Caused superficial scratching or reddening of the other person's skin (e.g. light slaps, hits, gentle pushes, hair pulling without force). First aid or medical attention was not needed)
3	=	moderate injury	Caused moderate tissue damage to the person(e.g. bites/hits/kicks breaking the skin or resulting in bruising). First aid but no medical attention needed.
4	=	serious injury	Caused serious tissue damage (e.g. cuts/wounds requiring stitching). Medical attention essential.
5	=	very serious injury	Caused very serious tissue damage (e.g. broken bones, deep lacerations/wounds). Hospitalisation and/or certified absences from work necessary)

CHALLENGING BEHAVIOUR CHECKLIST

Has .... exhibited any of the following behaviours during the past three months?

Challenging behaviours   **Enter appropriate numbers**
F=Frequency MD=Management Difficulty S=Severity

	F	MD	S
Pinching people			
Scratching people			
Hitting out at people (punching or slapping)			
Grabbing, squeezing, pushing or pulling people			
Kicking people			
Head butting people			
Pulling people's hair			
Choking or throttling people			
Using objects as weapons against people(eg knife)			
Throwing things at people			
Tearing other people's clothes			
Making unwanted sexual contact			
Injured self (eg head banging, eye poking/ gauging, biting, scratching self)			

	F	MD
Damaging clothes, furniture or other objects		
Smashing windows		
Slamming doors		
Shouting and swearing at people		
Making loud noises (eg banging, screeching, screaming)		
Threatening to hurt others (verbally of nonverbally)		
Taking food or drink from others		
Eating inappropriate things (rubbish, faeces, dangerous objects)		
Displaying ritualistic/repetitive behaviour (eg closing/opening doors, rearranging furniture, hoarding rubbish etc)		

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Engaging in stereotyped behaviour? (Body rocking, finger tapping, hand waving etc)		
Showing withdrawn behaviour (Difficult to reach or contact)		
Spitting at people		
Deliberately soiling, wetting		
Deliberately vomiting		
Smearing or flicking faeces (or anal probing)		
Exposing his/her body inappropriately (eg stripping or masturbating in public)		
Refusing to do things (eg eat or move)		
Absconding or trying to abscond from facility		
Setting fires		
Causing night time disturbance		

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Appendix 13: Support questions

SUPPORT QUESTIONS

Formal support
What is your relative's current use of day-time/evening services?

1   stays at home (i.e. no use of services)
2   attends a day centre
3   is employed
4   does voluntary work
5   attends evening activities
6   other (please specify)

_____

Satisfaction with informal support
Have you any friends or family outside the home, that you feel you can rely on to provide you with support? (Prompt: come round and sit with your relative when you want to go out; take your relative out for a period of time....)

1   yes
2   no

How satisfied are you with this support?

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

Emotional support questionnaire:

Have you been able to talk about your feelings and problems with at least one friend during the past month?

5   I could always talk freely about my feelings
4   I usually could talk about my feelings
3   About half the time I felt able to talk about my feelings
2   I usually was not able to talk about my feelings
1   I was never able to talk about my feelings

Have you been able to talk about your feelings and problems with at least one of your relatives in the last month?

5   I could always talk freely about my feelings
4   I usually could talk about my feelings
3   About half the time I felt able to talk about my feelings
2   I usually was not able to talk about my feelings
1   I was never able to talk about my feelings

If appropriate:
Have you been able to talk about your feeling and problems with your spouse or partner in the last month?

5   I could always talk freely about my feelings
4   I usually could talk about my feelings
3   About half the time I felt able to talk about my feelings
2   I usually was not able to talk about my feelings
1   I was never able to talk about my feelings

Appendix 14: Open ended questions

OPEN ENDED QUESTIONS

We know that looking after a relative with learning disabilities can be stressful, what if any, are the stresses for you?

Have these stresses changed over time, since _____ was a child?

How different do you think your life would be if _____ was not living at home?

Appendix 15: Respite questionnaire

RESPITE QUESTIONNAIRE

Pattern of use

(1) When did you last use respite care?

.... weeks ago

(2) How long have you used respite care from this service?

.... weeks/months/years

(3)How many times a year do you use respite care ?

....times

    Prompts: once a year / every six months (1-2 times a year)
                      once every two to four months (3-6 times a year)
                      monthly (12 times a year)
                      more often than monthly (> 12 times a year)

(4) and how long is this for in total?

....days

(All from: Jawed, Krishnan & Oliver (1992))

Parental satisfaction with respite services

(5) Are you satisfied with the discussion/planning that takes place between you and the respite staff?

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

(From: Stalker & Robinson (1994))

(6) Overall, how would you rate the quality of respite care your relative receives?

4   Excellent
3   Good
2   Fair
1   Poor

(From: Larsen, Attkisson, Hargreaves & Nguyen, (1979)

(7) To what extent does the service meet your needs?

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

(From: Larsen, Attkisson, Hargreaves & Nguyen, (1979))

(8) In an overall, general sense, how satisfied are you with the respite service your relative receives?

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

(From: Larsen, Attkisson, Hargreaves & Nguyen, (1979))

Benefits for carer of using respite care

(9) In what ways, if any, is using respite care service beneficial for you?
....
....
....
....
....
....
....
....
(From: Stalker & Robinson, (1994))